

EFFECTS ON FAMILY RELATIONS OF DECISIONS TO PLACE
ELDERLY RELATIVES IN INSTITUTIONS

BY

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This dissertation is lovingly dedicated to my husband, my children,
and especially to my mother whose sacrifices have been many.

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by

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This study examined the subsequent effects on family relations of family members' decisions to institutionalize elderly relatives. The sample consisted of twenty elderly females ranging in age from 60 to 95 who had been placed in a nursing home within one year of interview, their key family members who assumed the role of primary care givers, and a nursing home respondent familiar with the elderly subjects. Purposive non-probability sampling was done in two participating nursing homes. Intensive interviews were held to gather information on the importance of the family for the institutionalized elderly, to identify patterns of association, and to identify the nature of interaction which takes place between the institutionalized elderly and their family.

Among the findings in this study was the dysfunctional communications which exist between the elderly resident and their family members. Elderly residents were found to feel misunderstood by their family but as a rule did not make their feelings known. Instead, most tended to be compliant and accepting of their fate. Family members, on the other hand, felt less internal conflict if their elderly member

appeared to be adjusting to the nursing home placement. Contact of family members with the resident who lived alone prior to placement was as or more frequent since placement. Three levels of family involvement were identified based on the nature and quality of resident-family interaction. These patterns were designated detached, involved, and committed according to the intensity and extensiveness of the family's interaction with the resident. Residents with cognitive deficits that limited their ability to make their needs known tended to have a larger proportion of committed family members. Family members generally did not get involved with the institution on behalf of their elderly.

Relief from direct care which family members experienced with placement did not appear to improve family relations. Instead, family members tended to follow previously established relational patterns, although patterns of association--i.e., visiting frequency, shared activities, etc.--may have changed since nursing home placement. It is suggested that nursing homes adopt policies designed to promote resident-family communication and understanding.

CHAPTER 1 INTRODUCTION

Introduction

Today the most rapidly growing age cohort in the United States is that group of persons 65 years of age and above. Presently numbering more than 29 million (U.S. Bureau of the Census, 1987), it is estimated that their number will increase by 26% between 1980, when persons over 65 years old numbered 25.7 million, and 1999. More importantly, it is estimated that the number of persons 85 years and older will increase by 52% during this same period (White House Conference on Aging, 1981). A number of euphemisms have been attached to persons in the latter part of the life span, such as "old," "aged," "senior citizen," "elderly," and "gray minority." However, the expectation that one would live long enough to receive such a label is a fairly recent phenomenon. It results from a number of changes in the areas of health prevention, exercise, health care, technological advances in medicine, education, work safety, and nutrition which have taken place in our industrialized capitalist society. Advances in the above areas have contributed to the dramatic increase in life expectancy and general standard of living. The rapidity of growth in the aged population largely caught social policy makers and health care planners by surprise as this demographic shift was unexpected (Dunlop, 1979). This rapid growth in the aged population has familial, social, health, economic and political

implications for our society as it moves to define problems and anticipate, plan and implement responses to the needs of this group. Society is now struggling to come to grips with the multiple ramifications of this generational shift. And, perhaps because of the recency of the phenomenon, no viable and lasting solutions have yet been implemented. Several long term care task forces have been set up by the Department of Health and Human Services to develop policy options. These have not yet resulted in specific proposals (Dunlop, 1979). And the recently passed catastrophic health insurance does not address the costs of chronic diseases to which the elderly are prone (Brickner, Lechich, Lipsman and Scharer, 1987).

For those elderly who are economically secure, in relatively good health, and who retain their mental faculties and social resources, aging can be a continued celebration of life. Social and physical activities can be continued according to one's usual life style, and independence can be maintained. However, deterioration in health, economic and psychosocial needs are individually determined. For those elderly whose physical and/or mental health and economic base have deteriorated, the need for, and source of adequate health care becomes paramount. There comes a shift from independence--which is highly valued in our society--to dependence, a low-value status. In addition to the burden of deteriorating health, many elderly must struggle to adapt to an existence which is viewed by many in our industrial society as having little social value or reward. Gubrium (1973:136), in his discussion of incongruent expectations of the aged and effects on their

morale, notes that the elderly who face fixed restraints remain captives of circumstances. "Such elderly people suffer the dissatisfaction of negative self-judgements which is compounded by a personal inability to cope with and alter the conditions . . . making for the dissatisfactions."

The family has traditionally aided the elderly when their older members were no longer able to care for themselves. There is no doubt that family continues to be the source of care for most elderly today (Greene, 1982; Shanas, 1979). While family autonomy and independence are congruent with American political, economic and educational goals and values, they are hard for some families to attain, "particularly under conditions of economic or medical crisis at the end of life" (Streib 1972:5). One societal response to the needs of the ill and dependent aged has been the establishment of institutions designed primarily to accommodate the elderly. These institutions for the aged are called nursing homes, and a nursing home industry has developed in response to the demand for beds. In the decade between 1963 and 1973, there was a 117% increase in the available nursing home beds in the United States (Dunlop, 1979).

The 1987 Statistical Abstract of the United States indicates that 29,173,000 people, or 12.1% of the American population, was aged 65 years or older. According to the National Center for Health Statistics report on Use of Nursing Homes by the Elderly published in 1987, an estimated 1,315,800 persons 65 years and over were in 19,100 nursing homes nationwide. Forty-five percent of these nursing home residents

were 85 years and over, and women outnumbered men by a ratio of approximately three to one. In the state of Florida, for the 1980 census year, there were approximately 23,000 persons occupying homes for the aged.

Convergence of a number of factors has resulted in approximately 5% of the elderly population, 65 years and older, becoming residents of these institutions (Borgatta and McCluskey, 1980; Dunlop, 1979; Tobin and Lieberman, 1976). While the percentage of the elderly population who occupy institutions has been low and relatively stable over recent years, the fact that this cohort is increasing at a more rapid rate than is the general population suggests that there will be a considerable rise in the real numbers of elderly who will be institutionalized. In addition, the reduction in fertility rates may result in fewer family members available to care for the frail elderly (Treas, 1979).

Overview of Study

A number of researchers have examined the effects of institutional environments on the aged person (see, for instance, the 1981 NIMH annotated bibliography, Research on the Mental Health of the Aging, 1960-1976). Family attitudes toward aging and the aged, as well as patterns of family relations and assistance to the elderly, have been extensively examined by researchers (Bromberg, 1983; Maddox, 1975; Petersen, 1979). However, family involvement with their institutionalized elderly relatives has received less attention (Maddox, 1975:313).

This study is an exploratory examination of the subsequent effects on family relations of decisions by family to institutionalize elderly relatives. If aged persons have living family members, some of those family members become involved in the decision-making processes which may result in the placement of their relatives in institutions. Events, circumstances, and the existing and prior family relations of the actors involved are complex factors which determine whether a family member plays a greater or lesser role in finalizing the decisions making and affecting the actual placement. Sudden, severely incapacitating illnesses or accidents with only partial recovery potential and constant professional care requirements can render a decision academic for some families (Petersen, 1986). Other families, in conflict over their desire to have an elderly family member at home and the need to secure adequate care, decide to institutionalize their elderly only after every conceivable alternative has been exhausted. Yet, some make the decision to institutionalize only after their own health has been severely threatened by the constant care required by an elderly family member (York and Calsyn, 1977).

Many people view placing a family member in a nursing home as "putting them away." Indeed, for many elderly, the nursing home will be their last home. It is estimated that 17% of the people admitted to nursing homes die there during the first year of residency (McConnel, 1984). The public is continuously bombarded with negative reports of conditions in nursing homes. A number of these deficiencies have been substantiated by reports of the Subcommittee on Long-Term Care of the

Special Committee on Aging of the U.S. Senate. Listed in its 1974 report are deficiencies such as untrained and inadequate members of staff, lack of control of drugs, poor care, unsanitary conditions, negligence leading to death or injury and reprisals against those residents who complain, among others.

In this study, we will examine the extent to which both the elderly residents and their relatives share these negative views of nursing homes. Therefore, one primary assumption is that making a decision for institutionalization--whether made by a relative with full cooperation and agreement of the resident, or made unilaterally by a relative of the resident--creates a crisis within the family system which will impact upon future interpersonal relationships within the family. Changes in the social, emotional and physical environment created by institutionalization often demand modifications and adjustments in the patterns of family interaction. An example illustrates this point: If the elderly relative was living with the family at the time of placement, there can no longer be the constant presence of family members, nor the source of emotional involvement which was previously available; extra effort will have to be made by relatives if the elderly family member who is institutionalized is to be seen regularly. Both the elderly resident and the family members who provided care are likely to experience reactions to placement.

Hatch and Franken (1984:19) identified three periods of family stress associated with nursing home placement: decision making, admission of the parent (relative), and the emotional aftermath of

placement. Hatch and Franken, as do most researchers, looked at the adult children as the primary object of investigation in their study, and obtained no direct input from the elderly residents. Tobin and Lieberman (1976), who studied elderly subjects, found the negative effects of the elderly anticipating placement in an institution acted to strain and deteriorate their relationships with significant others, both family and friends. "The meaning of the losses connected with giving up independent living is separation; the experience is that of being abandoned" (Tobin and Lieberman, 1976:213). Of interest to us is the effects on family relationships of decisions to place elderly relatives in institutions.

The major objectives of this study are twofold. First, an attempt will be made to systematically collect and document information on the importance of the family for the institutionalized elderly member. This will be done by obtaining data from the nursing home residents and their key family members. And secondly, this study will seek to discover patterns of association and the nature of interactions which take place between the institutionalized elderly and their families.

The methodological approach adopted is in the research tradition of Glaser and Strauss's (1967) "grounded theory." In this approach, relevant categories are discovered by examination of the data rather than from a priori assumptions. In this study, focus is directed to the experiences of two actors: 1) the elderly persons placed in institutions, and 2) the relatives who were involved in the decision making process which resulted in institutional placement of the elderly

member. Respondents were encouraged to express their experiences, their joys, their sorrows, their fears and their ambivalences--in their own words, at their own pace. This permitted the sharing of a richer and deeper level of meaning than would be evident in a non-qualitative investigation. Perceptions of residents and family members were sought regarding (1) the nursing home, (2) the effects of placement on family relations, and (3) the nature and patterns of exchange between the family and older family members in nursing homes. A number of techniques were used in the collection of data, including observations, interviews, surveys and content analysis.

Significance of the Study

Investigation of the family relations of institutionalized elderly persons is timely as it relates to a practical problem of a significant and critical component of our population. Increasingly the effect of an aging population on the nation's economy is being debated in Congress and in the mass media. Federal expenditures for the elderly are of prime concern. Medicaid payments provide for more than half of the residents of nursing homes (Dunlop, 1979; Grimaldi, 1982; Scanlon, 1980). Huge health care costs increases have led to the government's institution of a cost control in the form of payment based on designated maximum length of stay for "Diagnosis Related Groups" (DRGs). There is growing evidence that DRGs have led to increased admissions to nursing homes as hospital stays are shortened (Petersen, 1986). Retsinas and Garrity (1986) suggest that because of DRG-based reimbursement,

hospitals will continue to send moribund patients to nursing homes rather than allowing them to die in hospitals.

The White House Conference on Aging (1981) suggested that families should be counted on to provide a larger share of the help and support for the elderly. Government assistance was viewed as being more appropriate for those who either have no family or whose families lack the necessary resources to deal with the physical, emotional and financial costs of maintaining their elderly members (1981:100). This position implies a policy move toward an increasing role of the family in the care of the elderly.

However, there is evidence in the literature that the family is already the primary provider of chronic health care for the elderly, providing both medically related and personal care (Sargl, 1985). The family is an important factor in the delay of or prevention of institutionalization (Greene, 1982; Shanas, 1979). Although family involvement with their elderly is well documented, the degree of closeness between the elderly and their families is not clear. Maddox (1975:318) has noted that the importance of the family in the long term care of the elderly has not been matched by appropriate research. Neither have the institutionalized elderly been asked about their family relationships. There is limited knowledge of the nature, extent and quality of family relationships with institutionalized elderly members. Nor is there sufficient information on how residents of nursing homes relate to their families. This study fills a portion of

this gap in research on the family and aging. Attention is now turned to literature relevant to these issues.

CHAPTER 2 LITERATURE REVIEW

Introduction

Old, elderly, aged, senior citizen, gray minority--all are labels frequently attached to persons in the latter part of the life span. The rapid increase in the number of persons in this group has begun to make a major impact on our society. As a result, no matter what the label, this component of our population has been increasingly commanding more attention in recent years from government, service agencies, and researchers. Aging presents life change situations, needs, and problems which, while perhaps not always unique to aging, do require approaches that take the factor of age into consideration. The lack of a coherent approach to the problems of aging coupled with the high relative costs to our society in providing for the needs of an aging population have worked to focus this attention (Dunlop, 1979).

Most estimates indicate approximately 5% of the elderly population are residents of institutions (e.g., see McConnel, 1984). Our society's general negative valuation of institutionalization, and the health, social, and economic implications involved with institutional care have tended to focus most research to date on the process, impact, and consequences of institutional life for the elderly and society at large (Borgatta and McCluskey, 1980; Dunlop, 1979; Tobin and Lieberman, 1976). The literature is replete with material on family responses to

aging members. There is considerably less information that sheds light on family involvement in placement decisions and with their institutionalized elderly.

Demographic Considerations

Whether 60 or 65 is used as a cut-off point, the relative proportion of persons in this age group to the overall population has increased. For instance, whereas in 1900 only 6.4% of the U.S. population was 60 years old and older, by 1975 this figure had increased to 14.8%. Florida's over-60 population is greater than 17% (Bradham and Pendergast, 1984). Not only has the older population grown, but it has experienced changes in composition. As recently as 1930, of those persons aged 60 years and older, the ratio of males to females was approximately one; by 1975 the number of males had dropped to 69 for every 100 females in this age group (Treas, 1979).

Another demographic change has seen an increase in those persons 85 years or older. In 1900, 4% of those 65 years and older were actually 85 years or older; by 1975 the figure had increased to 8%. These changes in the demographic composition of the older population have resulted in the likelihood of an aged relative being "a woman, a widow, and very old" (Treas, 1979:186).

A national survey of non-institutionalized aged persons indicates that "the immediate family of the old person, husband, wives and children is the major social support of the elderly in times of illness" (Shanas, 1979:18). The presence of family members to minister to

relatives is cited as making it possible for bedfast persons to live outside of institutions, thus underscoring the importance of the family for the elderly (Shanas, 1979).

However, Treas (1979) also notes the negative implications of continued low fertility rates on the availability of family support networks for the elderly, for lengthening of the life span is envisioned as being on a collision course with declining numbers of descendants. The risk of institutionalization increases with advancing age (Krause, 1982; Tobin and Lieberman, 1976). While overall approximately 5% of the total elderly population resides in institutions, less than 2% of those aged 65-75 are institutionalized, whereas 7% of those 75 to 85 years of age are institutionalized. For persons 85 and older, there is an increase to 16% in institutions (Tobin and Lieberman, 1976).

However, this 5% estimate of residency does not reflect the true proportion of individual elderly who will at some point in their life experience a period of institutional long term care. McConnel (1984), using a life-table technique to compute risk, indicates that few of us may have better than a 50-50 chance of avoiding institutionalization in a long term care facility. He cites estimates of less than 30 day stays for one-third of nursing home admissions, and a 74% discharge rate within the first year of residency. "A substantial influx of new residents must necessarily occur to sustain the levels of nursing home occupancy that have prevailed over the past decade" (McConnel, 1984:197).

There is no disagreement among demographers about the increasing growth of the aged population and the corresponding decline in the proportion of persons below 65 years. The composition of the aged population has changed such that there are considerably more female than male elderly, and an ever increasing number of persons surviving past 85 years (U. S. Bureau of the Census, 1987).

Neugarten (1976) found it useful to view older persons as members of two age-specific groups--the "young-old," those persons 55 to 75 years, and the "old-old," those persons 75 years old and older. The young-old were envisioned as relatively healthy, educated, and politically and civically active, while only a minority of the old-old are seen as active and productive. However, age alone is not a reliable indicator of the functional level of elderly persons. In later writings Neugarten (1982) modified her view, indicating that distinctions between the young-old and old-old were not so much of age, but of health and social characteristics. Petersen (1979), speaking of the family and age differentiation of the elderly in functional terms, draws from Neugarten's descriptive paradigm of the elderly. The "young-old" are those much less dependent on their children, and who resent interference in their lives. The "old" desire and need some assistance from children, but wish to make their own decisions. Finally, the "old-old" may be ready to have their children reverse roles with them and become their "parents in terms of caretaking" (1979:28). The important point here is that there is no age specificity, but rather a designation of

functionality in terms of independence-dependence which is frequently age-related.

Many factors are involved in the level of dependency and the age at which it occurs. Streib (1972) identifies four major resources which contribute to the strength of older families. These are physical health, emotional health, economic resources, and social resources. How needy, and how dependent a particular elderly person becomes can be viewed as being mediated by that person's peculiar mix of these identified resources, regardless of age. Some persons in their early sixties may fit the "old-old" model, while others in their eighties or nineties who live independently can be considered "young-old." Yet Schwartz (1979) points out the ease with which stereotypic expectations are communicated to and about the elderly. Family responses to aging will be more closely examined in the next section.

The Family and Aging

Treas (1979) notes that generational relationships have undergone historical change, but there is no definitive information that leads to the conclusion that societal transformations have "undermined family structure or weakened family ties" (1979:184). The family is the point of origin for every individual. It is a primary group with the fundamental characteristic of providing a critical interactional system for the individual (Sussman, 1977). Interactions among family members--parents, children and siblings--involve the playing of constantly changing reciprocal roles (Weishauss, 1979). At the same time each

member is changing and developing as an individual (Bengtson, 1979) in a dynamic interplay with the particular demands associated with where they are in the developmental process which continues throughout the life span.

There are three categories of tasks which Sussman (1977) outlines as being more structurally suited to be handled by families than any other social organizations. First, there are those tasks involved in the acquisition of general knowledge where family members instruct and communicate with one another in relation to everyday work, values, and competence to relate to and deal with others. Included in this category are physical needs and activities of daily living. Second are those tasks associated with problems and issues with which bureaucratic experts, as members of secondary groups, are not concerned. Included here are questions relative to mate selection, parenting, marital health, and assisting aged parents. Lastly are those tasks concerned with idiosyncratic events. This category includes infrequent accidental and "act of nature" events which generally cannot be predicted and to which the response can neither be predicted nor patterned. Examples include accidents, fires, or sudden death.

This structural suitability can be viewed as keeping family involvement as a factor in the events and processes of aging for all but those who lack primary family ties (Weishaus, 1979). Shanas (1979) estimates that 21% of the elderly over age 65 are without such ties. The particular nature and intensity of involvement, positively and

negatively, appears to be mediated both by our societal structure and that of the family as it moves through life stages.

Petersen (1979) indicates that developmental processes of relationships must be looked at when analyzing relationships and interactions of middle-aged children and their parents. He outlines a pattern which develops as the family moves through the life cycle. There tends to be an increase in interaction between married children and their parents when babies are born and during times of early economic struggle. This involvement decreases when the children are economically and geographically mobile and the parents are at the peak of their occupational and community involvement. Reduced involvement at this time may also be influenced by life style conflicts between teenagers and their grandparents. The pattern culminates in the retirement of the parents' health and vigor, and the beginning of incipient demand. Steinman (1979) refers to this period of increased involvement of adult children and aged parents as "rejoining."

Middle-aged children who experience demands from both the younger and older family members comprise the population between approximately 40 to 60 years of age. This group has been called the "sandwich generation" (Schwartz, 1979) or the "sandwich group" (Petersen, 1979) because it appears to be caught in the middle of two generations, the young and the old, both of which demand multiple role responsibilities.

Each transition in family structure and relationships requires varying degrees of modifications and flexibility to accept new roles and relinquish others if the family is to remain functional (Steinman,

1979). Schorr (1980) defines filial responsibility as the responsibility for parents exercised by children. If the middle-aged child has reached "filial maturity," a measure of growth has occurred which enables coping with feelings about the aging parent as well as feelings about his or her own aging. With filial maturation, there is also a feeling of responsibility to provide assistance to aged parents (Brubaker, 1985). Even if all family contact has been severed, the fact of one's family connections cannot be severed. However desirable reaching filial maturity is, it would appear that many have fallen short of that milestone. Aging and concomitant stress and demands of the latter phase of life often intensify those family conflicts which were not resolved with the passage of time (Brody and Spark, 1966). As long as there is not agreement on issues--frequently over levels of independence--conflict will exist in relationships between generations. These conflicts need not lead to abuse, but instead represent the importance of negotiations in seeking solutions to interactional problems between generations. External, professional help may be necessary to resolve these intergenerational problems.

Steinman (1979) identifies three types of conflict which may occur with increased interaction at rejoining of aged parents with their children. The first, continuing conflicts, are equivalent to Brody and Spark's unresolved conflicts. These conflicts have always been present between parent and child and either continued, worsened, or eased. Steinman calls the second type of conflict "new conflict" as these arise as a result of stimuli which occur with or after the increase in

interaction during the parents' aging. Examples are those conflicts which arise as a result of an aged parent moving into a child's home, or dependency needs being transferred to an adult child because of the death of a spouse.

Reactivated conflict is the third type which may occur at rejoining. Conflicts of this type were present before the adult child was emancipated, and though never resolved, seemed to have disappeared. These same conflicts or variations of them reappear with increased interaction. Reactivated conflicts most often revolve around two dimensions: independence/dependence and acceptance/rejection (Steinman, 1979:131).

Bengtson's (1979) autonomy vs. dependency is a problematic category in intergenerational interaction which is similar to Steinman's independence/dependence conflicts. He suggests three additional problematic categories: those of continuity vs. disruption, role transactions and equitable exchange. These categories will be examined more closely, relying primarily on the ideas of Bengtson (1979) and Steinman (1979).

Autonomy (Independence) vs. Dependency

Whereas a growing child's dependence on a parent for physical needs, nurturance and affection gradually declines, adult children continue to need acceptance and approval from the parent until that parent's death. Reciprocally, the parent is dependent on the child for affectional responses (Schwartz, 1979). Autonomy is an issue in family

relations for children at the beginning of the life cycle when there is a struggle for independence from parental control. Autonomy continues to be an issue at the end of the life cycle when aging parents experience increasing losses. These losses that parents experience through deaths, diminished physical and economic capacity, diminished friendship networks, and job identity tend to intensify dependency relationships with children and potentiate conflict. Both parents and children may struggle over the level of desirable mutual dependence. Bengtson suggests that "the challenge within the family is to allow relevant realistic, and equitable balance between dependency and autonomy as individuals change with the passage of time. The balance changes throughout life, and always requires a normal interval of negotiation as the individuals concerned adapt to changes in autonomy" (1979:50).

Acceptance/Rejection

It has been previously noted that adult children tend to continue to seek acceptance and approval from their parents. Rejoining, with its increased level of involvement, may reactivate manifestations of acceptance/rejection conflicts which have lain dormant over the years. Sibling rivalries, favoritisms, scapegoating and cross-generational coalitions (overly close attachment between two family members of different generations which exclude a third member) are examples. Left unresolved, these conflicts negatively influence relationships within the family. Steinman (1979) provides the example of a favored brother

who could "do no wrong" even though he contributed little. His sister, not so favored, did the vast majority of caring for their aged mother.

Continuity vs. Distruption

Bengtson (1979) notes the increasing importance of the continuity of family identity for those in advancing years. Geographic mobility, divorce, life style change and death are all potential disrupters of family identity. Mobility is an integral part of our culture. However, a national survey taken during the 1970's found that 77% of persons 65 and over with surviving children saw a child within the last seven days before interview. Of those who did not see a child during the previous week, 39% saw a sibling or other relative (Shanas, 1979).

Divorce, while disruptive in one sense, can lead to both a change in the nature of relationships and an increase or decrease in the number and quality of relationships within a family. At issue are relationships with daughters-in-law and sons-in-law who are no longer spouses of offspring. According to Bengtson "much continuity is maintained, and this calls for some rather delicate negotiations in terms of family get-togethers, birthdays, funerals and weddings" (1979:52).

Changes in life-styles do occur among younger family members and can be an affront to family values and traditions. Changes in religious and political affiliation and sexual expression can be powerful threats to family continuity and thus become issues for family negotiations. Finally death, which is an immediate, observable disruption, can also

become an affirmation of family continuity; funerals can present opportunities for family members to come together and reestablish disrupted relationships (Bengtson, 1979).

Role Transitions

Growing up and growing old carries with it concomitant changes in roles and expectations. Shifts occur in levels of parenting, work capacity, health, and social and economic circumstances. These role transitions require considerable adaptations on the parts of younger and older family members. Finding the right balance becomes a challenge.

Equitable Exchange

Equitable exchange concerns issues around the allocation of a just balance of giving and receiving between generations. This is a concern which influences the nature of relationships and involves the maintenance of equity in the provision of goods and services in the face of dependency of the older family member. There is the concern of children for what they can do for their aging parents; at the same time, aged parents question what they can give their children. Given the diminished resources available to the elderly to use as exchange, social and economic legacies may assume increased importance and may be used as a resource.

Areas in which conflictual intergenerational relationships are likely to occur have been identified. The nature and relevance of family involvement with the elderly will be considered next.

Family Involvement with the Elderly

It is unusual for multigenerations to live under one roof in our society. In fact, less than one in ten households is three generational (Hendricks and Hendricks, 1981). This does not, however, represent a shift in family patterns, for historically co-residence has always been a minority pattern (Laslett, 1972).

Studies which look at living arrangement preferences of elderly persons consistently find that the elderly prefer to live independently in their own homes (Peterson, 1979; Rosenmayr, 1977; Shanas, 1979; Sussman et al., 1979). Rosenmayr (1977) studied preference of living arrangements of Austrian elderly persons living alone. He found that, if a move became necessary, living in the same household with a relative seems to be readily acceptable where circumstances necessitate it, but it is not regarded as desirable. Rosenmayr's comparison between intergenerational living patterns and preferences suggests that the preference structure deemphasized both extremes of spatial closeness and distance, tending toward an optimal mixture of intimacy and distance. The similarity of Austria's industrialized society to ours also makes his findings relevant for our aging population.

In terms of spatial relations, 80% of older persons live less than one hour away from at least one of their children, and manage to see them at least weekly (Hendricks and Hendricks, 1981; Shanas, 1979). Middle-class families tend to live further apart than the lower-class because of increased mobility and career development concerns. However, mutual aid and contact patterns are comparable to other socioeconomic

groups (Hendricks and Hendricks, 1981:305). Thus, joint living does not appear to be the most important factor in the relationship between the elderly and their adult children, for, separateness of residence does not mean a lack of exchange between generations.

Rosenmayr (1977) identified three categories of instrumental aid which family members provide for the elderly: (1) household help; (2) shopping assistance; and (3) nursing in case of illness. The primary modalities of exchange are visitation, companionship, communication, emotional and social support, financial aid, gifts, child care, advice, and counsel (Sussman, 1977; Treas, 1979).

Sussman (1977) notes that exchanges are not universal or equal. Further, within all networks both conflict and cooperation exists (1977:14). There is often a burden bearer in the family (Brody and Spark, 1966). And while sons may be devoted, the major responsibility for psychological and physical sustenance of the aged has fallen to females. Daughters take in widowed mothers, run errands and provide custodial care (Treas, 1979). According to Hendricks and Hendricks (1981) daughters are the caretakers because they are more willing to suppress value conflicts with parents. But Bromberg (1983:84) suggests that for mothers and daughters, mutuality, interdependence and positive connection characterize their relationship in later life. Neither does frequency of intergenerational contact assure the quality of the relationship. In a review of studies which looked at contact frequency and affection, Weishaus found that frequent contact does not necessarily indicate affectionate feelings, "but may reflect feelings of

responsibility and obligation on the part of adult children as well as conscious or unconscious awareness of their parents' emotional needs" (1979:163). Both Maddox (1975) and Rosenmayr (1977) suggest the need for more research to differentiate between the role of families as sources of emotional support and sources of instrumental services for the aged.

The progressive losses associated with aging alters the exchange relationship between the aged and other groups. Dowd (1979) posits that rather than physical decline, this imbalance of exchange explains the disengagement from activity which has been consistently observed as occurring with advancing age. He states, "Because of [the aged's] limited power resources, the costs of remaining engaged--that is, the costs in compliance and self-respect--steadily increase" (1979:111). This disengagement from activities on the one hand is matched by an increased primacy of importance of emotional bonds with the family (Shanas, 1979).

Of studies reviewed which investigated the comparative salience of adult children for parents and that of parents for children, every study has found that children were more important to parents (Weishaus, 1979). Yet the elderly may risk alienating their kin if their emotional expectations and demands are greater than the family feels able to supply. Whereas the norm of reciprocity which exists in neighbor and friend interactions is viewed as enhancing the morale of participants because of feelings of equal contributions and value in the relationship, this equitable rate of exchange may not exist within the

family. The higher salience of children for parents, coupled with frequent contact, may lead to high expectations and demands by parents, which may lead to fear of rejection and resultant low morale (Weishaus, 1979). We turn now to examine family involvement in long term care of the elderly.

The Family and Long Term Care

Nursing homes represent the fastest growing component of those health care expenditures which greater than 50% is met with public funds (Dunlop, 1979; Grimaldi, 1982; Scanlon, 1980). Approximately 80% of nursing homes are for profit (Hendricks and Hendricks, 1981) and once there is placement in a nursing home there is little institutional impetus to return persons to their homes or to maintain adequate discharge policies which would reduce the length of stay (Hochbaum and Galkin, 1982). The steady increase in the number of old-old continues the expansion of the nursing home industry and of long term care beds (Hendricks and Hendricks, 1981). The White House Conference on Aging (1981), taking note of the economic burden of publicly funded care for the elderly, suggested that families be counted on to provide a larger share of the help and support for the elderly while reserving government assistance for those who have no family or whose families lack the necessary resources (1981:100).

It is estimated that only one in five, or 20% of the institutionalized elderly, are inappropriately placed in facilities that provide more intensive services than they actually require (Branch,

1980). Institutionalization when physically unnecessary, according to Petersen (1979), occurs only because of lack of family or community services. Branch (1980:5) notes that when the choice is between no care and too much care when some care is needed, too much care is chosen. The fact that a 5% institutional rate has remained almost constant over the years would seem to negate the idea that the burden of care is being shifted to institutions (Schorr, 1980:33). Family assistance given the elderly tends to maintain them in the community. Limitations of families as sources of continuing help for members who are disabled appear to be structural (in terms of size, mobility and conjugal focus) rather than ideological or attitudinal (Maddox, 1975). Another structural limitation relates to the present trend toward increasing numbers of women entering the workforce. The number of women available to care for ailing kin is being reduced and this may "portend a future in which the family can no longer offer day to day care to aged who can no longer care for themselves" (Treas, 1979:189). This societal trend is taking place at the same time that policy recommendations are toward avoidance of institutions and increased interest in home care (White House Conference on Aging, 1981).

Shanas (1979:174) has noted that persons without close family are more likely to be institutionalized when they are ill. Included here are the very old, usually women, and the never married. It is the family which is first turned to for help by the elderly, then neighbors and finally the bureaucratic replacements for families. That families are preferred as the primary source of care by the elderly is supported

by Sanders and Seelback (1982), who interviewed 450 Texan retirees. They found preference for care by family independent of age, cohort, gender, education and marital status.

As of today, the family remains the primary provider of chronic health care for the elderly, and it is the pivotal factor repeatedly identified as the determinant of whether an elderly person is institutionalized or not. Greene (1982) views family resources as the major predictor of individuals at risk for institutionalization. The lack of strong family ties and economic supports are more likely to result in premature admission to an institution (1982:59). Maddox (1975) suggests absence of an effective family unit is a crucial factor in institutionalization. He lists five important factors in the decision to institutionalize: (1) degree of impairment; (2) availability of a caretaker; (3) living space; (4) perceived danger to the elderly/ family unit; and (5) economic cost of alternative arrangement (1975:340). After the primacy of family, Greene (1982) views living arrangements as the second most critical variable in determining whether elderly impaired persons will be institutionalized. If the elderly live with spouse or children, he questions the influence of economic resources, family structure, quality of relationships and competing family demands on the decision to place elderly members in an institution.

While institutionalization would have been avoided in some cases but for the absence of a supportive network (George, 1984; Hendricks and Hendricks, 1981), many families endure enormous hardships and personal

strains to maintain their elderly relatives in the community (Butler, 1979; Cicirelli, 1983). When maintaining an elderly relative in the community is no longer feasible, no matter what previous sacrifices were made, institutionalization symbolizes the failure of family support to an aged member (Smith and Bengtson, 1979).

Sussman (1977) draws attention to the structural differences between the family and long-term facilities. Families are primary groups which respond efficiently to non-uniform, non-technical tasks, while institutions are bureaucracies which are organized to handle uniform, technical tasks. Institutions, because of their greater resources, are equipped to provide those required services necessary for continuity of care and maintenance of health for elderly persons with health deficits of long duration which require expertise the family does not possess. The institution takes over the technical tasks related to care giving; those technical tasks which are repetitive, require experts to handle them, and amass resources such as personnel, facilities and equipment. For some elderly persons, a long term care facility may represent the only logical place where their multiple needs can be met.

Yet institutionalization represents a last resort in providing care for an aged family member. This reflects the widespread negative views of institutional care which are held by a large component of our society, including the elderly and their families (Smith and Bengtson, 1979). There is the general opinion that institutional care is of substandard quality and tends to be mortifying and dehumanizing. Goffman's Asylums (1961), a work primarily about mental hospitals,

supports this view. Gubrium (1975) examined the social organization of care in a nursing home he called "Murray Manor." He provides graphic discussion of the process of providing care to the frail elderly. Using the unifying theme of the importance of place, he illustrates how separate social worlds of the staff and the residents can be maintained in a contained physical place. The institution's needs, and not necessarily those of the residents, govern how activities are regulated. Nursing homes are described as total institutions that promote homogeneous appearance of residents which act to reduce their individuality. More recently, Solomon (1982:285), in his discussion of learned helplessness, speaks to how institutions for the elderly "completely control all response contingencies of their resident's lives and wield an almost omnipotent power over the elderly living in them."

Glasscote, Beigel, Butterfield, Clark, Cox, Elper, Gudeman, Gurel, Lewis, Miles, Raybin, Reifler and Vito (1976) raise disturbing questions about the safe and accurate administration of prescribed medication in nursing homes. They cite a case of a diabetic woman whose insulin had been skipped seven times in a one month period (1976:76). Such an error can be life threatening. But while Glasscote et al. (1976) noted that nursing homes do have significant problems, they also pointed out that the nursing homes they studied were much better than was expected. They questioned whether the bad publicity nursing homes have had is an effort by our society to assuage guilt for diminishing the status and self-

esteem of the elderly by directing anger at "those recesses of society to which we have relegated so many of them" (Glasscote et al., 1976:148). There are serious questions about the quality of care actually provided the elderly in nursing homes. Hendricks and Hendricks (1981:327) posit that many long term care institutions increase efficiency at the expense of emotional needs and personal integrity. And George (1984:351) notes that federal regulations primarily cover structural and staffing issues which are important, but do not guarantee the quality of care.

Hirschfield and Dennis (1979), in their study of issues involved in relationships between adult children and their aging parents, found the subject of guilt to be dominant and pervasive. Children expressed difficulty in coping with and resolving feelings of guilt in conjunction with feelings of responsibility for their parents, especially related to decisions to place parents in institutions. The subject of guilt feelings relating to decisions to place in institutions is repeatedly echoed in the writings of those concerned with aging. The studies by Brody and Spark (1966), Dobrof (1977), Schwartz (1979), Tobin and Leiberman (1976), and Weishaus (1979) are a few examples of the published literature on this topic.

Factors of guilt feelings, negative estimations of institutions, and increased requirements of care of the elderly relative all converge to create a crisis situation at the time of making decisions about placement. Tobin and Leiberman (1976) found that the decision making

process prior to actual placement stimulated the development of institutional effects in their elderly subjects, effects which had been considered to occur only after admission to an institution. The elderly person anticipating institutionalization is described as becoming progressively cognitively constricted, apathetic, unhappy, hopeless, depressed, anxious and less dominant in relationships with others--a profile very much like the stereotype of an elderly person in an institution. Also noted were adverse changes in relationships with significant others. This adverse change in relationships was the single largest difference between the sample of elderly in the community and the sample of elderly on an institution waiting list, suggesting the importance of the social system in decisions to institutionalize. Social workers have recognized these adverse responses to decision making and institutional placement. Strategies are being developed to assist the elderly and their family members during these crisis periods (Bogo, 1987; Dobrof, 1986; Rakowski and Clark, 1985).

Shanas (1962) notes that almost all older people view long term placement with fear and hostility, and, no matter what the extenuating circumstances, view the placement as rejection by the family. Dobrof (1977) stresses that entry into a long term care facility is never an easy time for the elderly person or the family, but disagrees with Shanas's view that the elderly always interpret placement as rejection by the family. Dobrof suggests that in order to understand the meaning of the experience, one must understand the circumstances of the entry

into the institution, the path taken by the elderly person and family, and the process of decision making.

Admission to a long term facility need not indicate a disengagement from nor a diminished involvement of the family with their elderly members. Instead the need for perpetuating and redefining meaningful family relations is accentuated (Mattson et al., 1978). The issue becomes one of "how structurally different organizations (family and human service organizations), having identified areas of common concern, and having need for one another to reach the objective of this concern, might control their hostilities and accomodate their differences" (Sussman, 1977:6). In this instance, the ailing aged family member is the "area of concern."

Contact with close persons may have the most important meaning for an elderly person in an institution (Butler, 1979). However, policies enacted by long term care facilities can act to either facilitate or discourage family involvement with their elderly relatives. For example, limited and inflexible visiting hours tend to inhibit potential family involvement (Mattson et al., 1978).

Sussman (1977) views the kin network as an important mediating socializing and decision making structure for the elderly which links them with the bureaucracy--in this instance the long term care facility. When the family remains involved with elderly members in institutions the quality of care appears to benefit (Shuttlesworth et al., 1982). It is in situations where the bureaucratic structure is

hostile to family concerns and wishes that the family can act to modify the differences, and in so doing lend to the elderly family member a modicum of power in an otherwise powerless situation. In order to affect the desired accomodation, the family may choose to either deal directly with bureaucratic organizations or use linkage groups such as advocacy organizations (Sussman, 1977).

An area of concern for families of elderly in nursing homes is the rate of staff turnover. Halbur's (1983) study of nursing personnel turnover in 122 nursing homes found a 68% annual rate of turnover for nurses' aides, and an average length of employment of only 6.2 months for this job level. That rate of turnover is over three times the average of 22% annually for workers in other service producing organizations (Halbur, 1983:397). The turnover rate of other nursing personnel is not as high as nurses' aides, but at 51% for licensed practical nurses and 36% for registered nurses, there is cause for concern. Limited rewards, especially low wages contribute to high turnover rates for nursing personnel. Structural variables such as type of nursing home ownership, size and general economic activity also influence turnover. There are higher nursing personnel turnover rates in large, for profit nursing homes, than in smaller not-for-profit nursing homes (Halbur, 1983). Family members want assurances that their elderly are being adequately cared for. However, the rapidity of staff turnover would tend to lessen the extent to which the nursing home bureaucratic organization is able to efficiently and humanely carry out its mission to provide care for the elderly. Continued involvement of

family members with their elderly is suggested by Shuttlesworth et al. (1982) as one means of assuring quality of care.

Conflicts may arise about the role the family members should assume in their relationship with their elderly family member if there is disagreement between the family and the institution as to which tasks fall within whose purview. In a study which looked at whom nursing home administrators and relatives of residents felt was responsible for performing essential tasks, Shuttlesworth et al. (1982) found that in almost every case where response discrepancies were observed, both within and between groups, the item concerned a non-technical task. In general, the administrators tended to assign families less responsibility than the families assigned themselves. The researchers conclude by indicating closer partnership between families and institutions may depend on two factors: "(1) the degree of clarity regarding the subdivision of tasks between nursing home staff and families, and (2) the degree to which institutions encourage and support family involvement in appropriate aspects of care" (1982:207).

Exactly to what extent institutional policies and attitudes negatively affect family involvement with their elderly is not clear. That families do remain involved with their institutionalized elderly and may realize positive consequences from institutionalization is supported by the research of Smith and Bengtson (1979). Their study calls into question the common stereotype that institutionalization represents a breakdown in family solidarity.

These researchers interviewed parents who were institutionalized and their children (N = 100). "Ideal types" were identified which reflect improvement, continuation or deterioration in family relations following institutionalization. The majority of parents and children expressed either an improvement in or continuation of close family ties following institutionalization, suggesting that the institutionalization of the elderly family member served to strengthen family relations. Reasons posited for the positive consequences observed include: (1) alleviation of acute strains on the family; (2) improved physical and/or mental conditions of the parent with 24 hour care; (3) spending time with parents, knowing basic needs were provided for; and (4) the parents' development of new relationships with other residents which lessened the reliance on family for interpersonal interaction.

The fact that this study was done in an institution with very high quality of care, middle class clientele and policies which actively encourage family involvement severely limits the extent to which these findings can be generalized. Further study is clearly needed to discover the effects on family relations of decisions to place elderly persons in institutions. In addition, as most of the literature focuses on parent-adult child relations in aging, not enough is known about the involvement of other relatives in decisions to institutionalize, nor is it known what effects the decision has on those relationships.

This review of the literature has provided evidence that the risk of institutionalization increases with age (Krause, 1982; McConnel, 1984; Shanas, 1979; Tobin and Lieberman, 1976) and declining economic,

social, physical and mental resources which may have previously been sources of family strength (Greene, 1982; Maddox, 1975; Streib, 1972). Conflict is normative within family systems (Bengtson, 1979; Brody and Spark, 1966; Steinman, 1979) as are changes in perceived sense of closeness at various stages of the life cycle. After a period of less intense relations with young adult children, elderly family members tend to rejoin (Steinman, 1979) with their middle-aged children who are sandwiched between the older and younger generations (Petersen, 1979; Schwartz, 1979).

With aging there tends to be decreased involvement or disengagement from previous activities and increased primacy of family (Shanas, 1979; Weishaus, 1979). Parents see at least one child weekly or more frequently (Hendricks and Hendricks, 1981; Shanas, 1979) and depend on children for affectional responses, while adult children continue to seek parental approval (Schwartz, 1979).

When help is needed the elderly prefer that family provide that help (Greene, 1982; Sanders and Seelback, 1982; Shanas, 1979). There is evidence that family is important in preventing institutionalization (Shanas, 1979), yet guilt is viewed by a number of researchers as being a dominant issue between parent and adult child when institutionalization is considered (Brody and Spark, 1966; Dobrof, 1977; Hirschfield and Dennis, 1979; Schwartz, 1979; Tobin and Lieberman, 1976; Weishaus, 1979). Each family usually has a female burden bearer (Brody and Spark, 1966; Hendricks and Hendricks, 1981; Treas, 1979) who,

according to Hendricks and Hendricks' (1981), becomes the burden bearer because she suppresses any past, present or future value conflicts. On the other hand, Bromberg (1983) disagreed with this concept of value conflicts, finding instead that mutuality, interdependence and positive connection characterized mother-daughter relationships in later life.

Shanas (1962) indicated that placement in an institution is always perceived by the elderly as family rejection. Dobrof (1977) and Mattson et al. (1978) disagreed. They posited that the meaning of the institutional experience depends on the path taken by the elderly and the family in the process of decision making. Moreover, the research of Smith and Bengtson (1979) suggested that family relations may actually be strengthened by institutionalization of the elderly as the family was relieved from the strains of constant care giving.

For the most part there is agreement in the literature that the elderly, because of the series of social, economic and health losses to which they are subjected, have reduced resources and exchange power by which an equitable exchange relationship can be assured. However there is a paucity of information in the literature on how important the family is to the elderly in long term care institutions. Patterns of exchange between family members and their elderly loved ones in institutions have not been addressed. There is neither sufficient information on patterns of association between family members and the institutionalized elderly, nor the extent of affectional feelings involved with patterns of association. We still have much to learn

about how family and the elderly are affected by the experience of decision making, placement and adjustment to placement in institutions. This study is designed to document relationship of family members with their institutionalized elderly, thereby providing insights into the issues raised.

We now turn our attention to the methods employed to study these issues.

CHAPTER 3 METHODS

The Research Question

The decision as to how to best contribute to the social science research literature on delivery of health care to chronically ill populations was not an easy one to make. My professional nursing background and clinical practice oriented my concerns toward the mentally ill and institutional treatment settings. I had visited a number of researchers, talked with them about their research involvement, and generally sought to narrow and define the direction I wished to take.

It was through this process that I became acquainted with a proposal that former University of Florida Professor Douglas Bradham was in the process of submitting in response to a call for proposals by Florida's Department of Health and Rehabilitative Services (HRS). Florida was interested in identifying the social, economic and health characteristics of recent nursing home placements in the state and wanted data upon which to base its policy decisions. Dr. Bradham offered me the opportunity to participate in conducting this study if his proposal were accepted, with the thought that I might draw from the larger study a smaller issue which demanded more focused and in-depth study.

Dr. Bradham successfully competed for the HRS study contract, and I was able to participate in the project from its developmental stages onward. At the beginning of our collaboration it was my hope that residents with psychiatric problems could be identified through the preliminary data collecting process used by the study. These aged residents with psychiatric disorders would then be the object of my investigation. As diagnostic categories were not included in the preliminary data, it turned out to be impossible to determine which residents had psychiatric disorders. And so this idea was abandoned. But my interest in nursing home residents led to literature searches which revealed a lack of information on the importance of the family for elderly persons in institutions. My already strong clinical and academic interest in family systems, coupled with more intimate involvement with the problems of the institutionalized aged, led me to focus on the research topic presently under consideration. Specifically, I decided to examine the importance of family for the institutionalized elderly by investigating the effects on family relations of decisions to place elderly family members in institutions.

The Approach

As we attempted to understand the social processes involved between the institutionalized elderly and the family in the Florida Nursing Home Placement Study (FNHPS), we decided that qualitative methods would provide a needed richness of data that could not be obtained through the

use of survey questions with fixed response categories. Based on this rationale, most (but not all) techniques for gathering data were qualitative.

Accessing the Settings

The subjects of this study are nursing home residents and their families, specifically, their primary care givers (PCG). In order to identify the subjects, entry had to be made into nursing homes. The first step taken was to identify all nursing homes within the Northern Florida metropolitan area targeted. During the summer of 1984, when data were being collected, there were five nursing homes in the area under consideration.

Initial telephone contact was made with the administrator in each nursing home. I briefly told them of my wish to have their organization involved in a research study, and arranged an appointment to visit the home and give more detailed information. Each of the five nursing homes was visited. The administrators were provided with an introductory letter from the University of Florida Sociology Department, signed by the Graduate Research Professor, Gordon B. Streib, Ph.D. (see Appendix E). I outlined in detail the study's objectives and the process by which data would be collected. Reassurance was given about confidentiality and the sensitivity with which I would approach residents and their families. My background as a nurse was stressed so that it was clear that I understood their concern about protecting their clients.

Out of the universe of five homes, only two allowed access. For purposes of this study, the two cooperating nursing homes will be designated University and North. Of the three homes that refused access, the administrator of one expressed concern that families would object to their elderly residents being used as subjects. Residents of the home had recently participated in the FNHPS, but the administrator indicated this was only because it was sponsored by HRS. The administrator further stated he would need to discuss the idea with his associates before giving approval. Approval was not forthcoming.

The administrator of the second nursing home had few questions about my mission, but indicated he would need to get clearance from his corporate headquarters before I could proceed. After two weeks without a response, time constraints made it counterproductive to pursue arranging this access. No further contact was made.

The administrator of the third nursing home was in crisis the morning of my appointment. His daughter had taken seriously ill and was in hospital. My time with him was brief. I explained salient points, and at his request, left a copy of the research proposal. A commitment was made to present the proposal for review by the homes' "Education and Research Committee." A month later I received a letter denying access because "It (the proposal) does not fall into the research categories we feel are appropriate to our overall program at this time."

Being able to sample all available nursing homes in the area would have permitted comparisons of the effects of structure and organizational control on family-resident involvement. However, I was

pleased with my reception by University and North nursing homes. Both administrators were interested in what I proposed, projected images of progressiveness and concern for the positive effects research can have on the nursing home industry, and gave immediate access. In addition they both identified persons on their staff who would assist me if I had questions or needs. These persons proved to be most helpful.

The Settings

Even with a small number, I was struck by the range of ambience evident in the five area nursing homes. On one end of the spectrum was an elegantly furnished, carpeted, color coordinated and comfortable setting which showed no immediate indication of its mission, i.e., the care of old folks. The lobby was spacious with comfortable chairs, tables, centerpieces and lovely paintings. The architectural design kept residents' rooms and activity areas from immediate view. The impression was that of entering a fashionable hotel. On the other end of the spectrum was the home where one's senses were bombarded with unpleasantness upon entering the door. The small lobby was sparsely furnished. Those chairs present were in poor repair. The walls were dirty and long overdue for painting. Besides these structural deficiencies, the human misery was clearly evident. There was no escape from the strong odor of urine that permeated the air. A number of the residents were in a room in view of the lobby. Most were just sitting, clad in gowns.

Happily the other four homes did not present such a depressing picture. One of the four had a hospital like appearance, with design and furnishings seemingly selected more for utilitarian values than those of comfort and aesthetics. The remaining nursing homes had lobbies which appeared comfortable and homey. But they too were designed so that casual visitors would not encounter the residents. As has been noted, only two of the five homes permitted access. Future comments will be limited to these two nursing homes, which we have designated University and North for comparative purposes.

University and North were the latest homes to open in the area, University having opened in 1982 with a 180 bed capacity, and North in February of 1984 with a 120 bed capacity. Eleven percent of the residents at University, and 26% at North are private pay. All the other residents are supported by Medicaid. Both are under private proprietary control, for profit, and are considered by the study subjects to be the nicest of the five area homes. While University has some degree of organizational stability, one gets the impression from observations and from respondents that North is struggling to attain this stability. Both homes have locational advantages. University is located across the street from two medical centers and is only a few minutes drive from the hub of the commercial center of the area. North is next to a private hospital and across the street from the major shopping center in the county. The two locations both have the advantages of close proximity to immediate emergency medical care should

it be needed, as well as being close enough to population and activity centers to facilitate resident-family activity outside the nursing home.

My observations allow several comparisons. First, it appears that the activity level--residents moving around and doing things--was higher in University than in North. North had more space--sitting rooms, day rooms--but few people used this space. On the other hand, University was noisy. There was piped music, radios, TV, the clatter of things being moved around, and an intercom that frequently blared messages. I was aware of the noise because it occasionally created some problems with completing interviews. The level of noise became even more evident as the interview tapes were reviewed in the more quiet setting of my office.

The administrators of both homes were warmly receptive of my involvement with their organizations. They introduced me to the staff member with whom I would work and assured their full cooperation. I had very little interaction with either administrator after this initial contact, other than occasional greetings in my comings and goings as I collected data. It was the admissions officer in North and a social worker in University who answered more of my organizational questions and cleared the way with the staff for my work. Whenever I went to the nursing homes to interview residents during the summer of 1984, I made it a point to locate the charge nurse and notify her of my presence. I encountered no resistance to my activities from any of the staff at either nursing home. Some were curious as to what I was doing, but mostly I was tolerated or ignored.

All resident interviews took place in the nursing homes. Most often the resident's room provided the privacy needed to talk in confidence. Occasionally a roommate was present or I encountered the resident in another area of the home. When this occurred, alternative places--some more suitable than others--were found. Examples of these "other" places include the day room, dining room, staff pantry, and the end of a hallway. This last was by far the least suitable of places. Nonetheless, no matter what the setting, all the interviews were done in private.

Family members were also interviewed in a number of different places as it was necessary for me to accommodate the family members' schedules and needs. Therefore I met some family at the nursing homes, (n=2) but others were met in their offices (n=4) or homes (n=4). One family member was interviewed in the dining room at his place of work, and another was interviewed in my office. Those who could not be scheduled for face-to-face interviews because of distance, time constraints or scheduling difficulties, were interviewed by phone (n=8).

The Subjects

Criteria for selection of subjects were developed from previous findings in the literature. Subjects were limited to females based on census data indicating females outnumber males in nursing homes by 3 to 1. Focusing on females eliminates any sex difference that might confound the results. Sixty is the lowest age generally accepted for the designation of "elderly". No upper age limit is designated. No

person was included who had been a resident over a year; this maximized respondents' recall of the circumstances, events and responses experienced during the period of decision making, nursing home placement, and adjustment to placement. Neither physical nor mental condition was reason for exclusion as a case. To have been selected as a subject a person would have had to be: A resident of one of the targeted area nursing homes, female, placed between July 1, 1983 and June 30, 1984, and have an involved relative willing to participate in the study. Interviews with all residents and their families were conducted in the summer of 1984.

Based on these outlined criteria, purposive non-probability sampling was done in the two participating nursing homes, University and North. A more detailed account of the sampling process will be presented under the section on procedures.

The Instruments

An interview protocol was designed for dual use with residents and family members (see Appendix A). The selection of the interview protocol rather than a structured questionnaire provided the researcher with the freedom to encourage respondents to express ideas and feelings unrestrained by predetermined response categories. The protocol was designed by drawing topical areas from the literature which have been identified by previous researchers as important in the assessment of family relations. An important resource was Bengtson and Schrader's (1982) compilation of research instruments. The first section of this

study's interview protocol explores feelings about the nursing home. It includes prompts to encourage expression of likes and dislikes about the home, the staff, the administration and the rules. The more impersonal topics were purposely placed first to allow the interviewer to establish a working relationship with the respondent before more personal and sensitive areas were explored. The first section also includes questions about the problems, events and feelings leading up to the decision to place and actual placement in the institution. Six of these questions are taken from the FNHPS.

Section two of this interview was concerned with family association. Indicators assessed have to do with living arrangements prior to the nursing home, the kind of contact between family members and their activities. The next section, section three, relates to family exchange, which culled data on family helping behaviors. Section four, family sense of duty, sought to determine the extent to which family members felt obligated to each other. The fifth and last section of the protocol dealt with family members affectional feelings. Information on basic demographic variables of age, race, education and job history was collected last.

A structured questionnaire was developed for completion by a nursing home professional familiar with the subjects (see Appendix B). This is a 19 item checklist which parallels the study protocol in areas of family associational, exchange and affectional variables, and includes items pertaining to residents' activities of daily living. This instrument was intended as a means to verify information provided

by the subjects. At no time did the nursing home respondent have access to interview data.

The Procedure

Resource limitations common to all dissertations dictated that the study be restricted, somewhat arbitrarily, to a goal of twenty cases. Each case included two subjects, the nursing home resident and the key family member--the family member most involved with the resident. Key family members were identified by the social worker for those subjects at University, and from their charts at North. These were then validated by telephone contacts. Cases were to be divided evenly between University and North, and were to be selected based on non-probability sampling of the participating homes residents who fitted the criteria and whose key family members were willing to participate.

However, the administration of University insisted on retaining control over case selection. I preferred that this did not happen, but felt that insisting otherwise might threaten the entree I had already gained. The selection criteria were shared with the social worker assigned to do the selecting of cases. Before I was allowed to see any resident, the social worker would first discuss the project with the resident, find out whether she was willing to participate, and then call the family to determine their willingness. After this was done, I received a list of the ten cases with names and phone numbers of key family members from University. There were no alternates. It was my impression that this retention of control was an expression of

protection of the interests of residents and their family by the nursing home's administration.

Whatever the motives, as the interviews began I discovered the sampling process to be problematic. One of the selected subjects did not meet the age requirement, and another refused participation. Therefore, instead of the planned ten cases from University, there are only eight. To compensate, twelve cases instead of ten were drawn from North.

At North the selection of residents for interview was simpler. First the charts of all 60 female residents were reviewed and a list made of all residents who met the stated criteria. These totaled thirty-three. Of those 33, ten had closest relatives who lived 20 miles or more in distance from the home. These ten were separated out and held in reserve in the event that I failed to find sufficient number of willing participants within the 23 residents having key family members in the immediate area. Information on the name, address and phone numbers of the key family members was transcribed to individual file cards as the original list was being compiled. I next set about calling family members randomly from the information on the cards until 12 willing participants were identified. All 12 cases identified from the North nursing home came from the 23 possible cases within the immediate area sampling frame of a twenty mile radius. Preference was given to these area relatives in order to facilitate access for interviewing.

Often repeated attempts were made before telephone contact with the key family member was successful. A modification of the data tracking

sheet from the FNHPS was used to document the outcomes of these attempted contacts. Of the 23 possible cases drawn from North nursing home, I was able to contact the key family member of all but one. Of the remaining 22, twelve were selected as cases, seven expressed willingness to participate, but their conflicting schedules precluded their participation. Several would be out of the area during the interview time frame. In the case selection process for both University and North nursing homes, I encountered only four refusals--two from residents, and two from family members.

Once a relative agreed to be interviewed, a mutually agreed upon date, time and place of interview was set. If circumstances of time and/or distance prevented a face-to-face interview, time for a telephone interview was arranged.

Interview time for residents was not as problematic. They were, after all, a near captive audience. For the most part, the interviews were done without scheduling problems, the interview time determined more by my own competing commitments. When interviews were face-to-face, written consents were obtained before the interview began. Recorded verbal consents were obtained when interviews were by phone (see Appendix D). To assure accuracy of information, both written notes and tape recordings were made of each interview.

Of the twenty cases in the study, interviews were successfully completed with both the resident and the key family in fourteen cases. Family interviews were completed in all twenty cases. Five residents were mentally unable to cooperate meaningfully with the interview.

Although unable to effectively communicate, time was spent with each observing the extent of their incapacitation. The sixth resident who was not interviewed became worse physically and was hospitalized before an interview was arranged. The study design called for physical and/or mental condition not to be cause for exclusion as a case. Residents who were not able to cooperate with interview are retained for analysis so that the impact of their condition on family members can be assessed.

Managing the Data

Written notes and tape recordings were made of each interview. After the interview, the recordings were reviewed. Written notes were corrected and updated. Copies were made of the written notes and the originals placed in a safe place. An index copy was left intact and was referred to throughout the sorting and analysis of the data. Other work copies were cut up and cataloged by question and emerging categories. Key words were extracted from each substantive area of inquiry. This permitted the construction of a matrix for the examination of the content of each interview as patterns of responses became more evident.

On another card, other notations about the interviews were kept. I specified where the interview took place, who was present, the reaction of the interviewee to me and the interview content. Also noted were my reaction to the interviewee, plus any other information about the respondent--objective and impressional--which appeared important. The findings will be presented in the next chapter.

CHAPTER 4 FINDINGS

Demographics

A summary of the distribution of the demographic variables in the study sample follows. Of the twenty cases included in the study, one consisted of a black family. The other nineteen pairs were white. As shown in Table 1, 85% of the residents (n=17) were 75 years old or older. This percentage of 75 years and older is 12% higher than the Florida nursing home age structure found in the 1984 FNHP study. Ages of the family member classified as primary care givers were fairly evenly distributed between those below 55 years, those 55 to 64 years old and those 65 years and older.

Table 1
AGE DISTRIBUTION OF RESIDENTS BY AGE OF PRIMARY CARE GIVERS

Resident Age	(N=20)	Primary Care Giver Age (N=20)		
		Below 54	55-64	65 and above
60-64	1	1	---	---
65-74	2	1	---	1
75-84	9	5	2	2
85 and above	3	---	5	3

Of the seventeen residents 75 years and older, twelve had key family members 55 years and older, and five had key family members 65 years and older. There were no key family members below 55 years of age for the eight residents 85 years and older.

Most ($n=11$) of the key family members interviewed were male. Sons were identified as key family in five cases, although in each of these families there were also daughters. Based on the literature reviewed above on key relatives, this is an unusual finding. While males were the most frequent care givers for residents 75 years old and above, for those residents 85 years and older, the most frequent primary care givers were female (see Table 2). Eight sons, one grandson and two husbands were primary care givers for the eleven residents cared for by males. Six daughters and three sisters were the primary care givers for the remaining nine residents. Brothers were not identified as key family by any of the nursing home residents. The high proportion of male primary care givers is likely a product of the small sample size and a geographic accident that male relatives were more accessible to residents than female relatives.

As specified in the research design, all residents had at least one family member living within a twenty mile radius of the nursing home. The data presented in Table 3 indicate the family structural dimensions of the subjects. Half the sampled residents also had other family members besides the primary care giver living in Florida.

Data on the highest education completed was missing on three residents. The level of education completed by the other thirty-seven subjects is given in Table 4.

Table 2
AGE DISTRIBUTION OF RESIDENTS BY SEX OF PRIMARY CARE GIVER

Resident Age	(N=20)	Primary Care Giver (N=20)	
		Male	Female
60-64	1	---	1
65-74	2	1	1
75-84	9	7	2
85 and older	8	3	5

Table 3
FAMILY STRUCTURAL DIMENSIONS OF RESIDENTS

	Number of Residents with Kin
Sons	15
Daughters	13
Sisters	10
Brothers	5
Husbands	2
Parent	1

Table 4
HIGHEST LEVEL OF EDUCATION COMPLETED BY RESPONDENTS

Subject	Less than Grade School	Grade School	High School	College	Advanced Degree
Resident	1	6	6	4	---
Key Family	---	2	8	6	4

As would be expected, the level of education of key family members was higher than that of their aged loved ones.

Sixteen, or 80%, of the residents were widows. Two were married, and two had never been married. In regard to living arrangements of residents prior to nursing home placement, the data as presented in Table 5 revealed the following variations by resident age.

Table 5
PRE-NURSING HOME LIVING ARRANGEMENT BY RESIDENT AGE

Living Arrangement	Age			
	60-64	65-74	75-84	85 and above
Alone	---	1	4	2
Daughter	---	---	1	4
Spouse	---	1	3	---
Son	1	---	1	1
Sister	---	---	---	1

Thus although Table 2 indicates that males are most frequently the key family member of the residents, when those residents who lived alone or with their spouses prior to placement are eliminated, females took their aging loved ones into their homes more often than did males.

Perceptions of the Nursing Home

Most residents tended to describe their likes about the nursing home in non-specific complementary terms such as "nice and "pretty." Their family members were more pragmatic and specific. What they like most about the nursing home is its appearance or cleanliness, its proximity to a hospital, and the availability of professional help if the need arose. Expressed likes about the nursing home by general categories are presented in Table 6, while Table 7 shows the number of likes expressed by subjects.

Table 6
DISTRIBUTION OF EXPRESSED LIKES ABOUT THE NURSING HOME
BY SPECIFIC CATEGORY AND RESPONDENT

Category	N	Respondent	
		Resident (N=14)	Family (N=20)
Physical Environment	35	11	24
Services	29	10	19
Location	11	1	10
Other	6	3	3
Everything	3	2	1

NOTE: Some respondents expressed more than one like

Table 7
PERCENT DISTRIBUTION OF EXPRESSED LIKES ABOUT THE NURSING HOME

Likes	Respondents			
	Resident (N=14)	%	Family (N=20)	%
None	2	14	1	5
One or more	12	86	19	95
Two or more	9	64	16	80
Three or more	4	29	9	45
Four or more	1	7	6	30

General categories of expressed dislikes about the nursing home are presented in Table 8. Table 9 shows the number of dislikes expressed. Five residents and three family members expressed no dislikes about the nursing home. Most of the dislikes expressed by residents about the home related to food, followed by the lack of privacy. Concern for the type and quality of food and the lack of privacy was also expressed by some family members. However, low staff-resident ratios were a problem for 35% of family members (n=7). Moreover, three family members expressed the belief that prescribed treatment was being neglected. For example, there was concern that medication was not administered on a timely basis, and that regular exercise was not provided stroke victims.

Table 8
DISTRIBUTION OF DISLIKES EXPRESSED ABOUT THE NURSING HOME
BY SPECIFIC CATEGORY AND RESPONDENT

Category	Respondents		
	N	Resident (N=14)	Family (N=20)
Services	18	6	12
Physical Environment	9	3	6
Staffing	8	---	8
Interpersonal	6	5	1
Other	3	2	1
None	8	5	3

NOTE: Some respondents expressed more than one dislike.

Table 9
PERCENT DISTRIBUTION OF NUMBER OF DISLIKES EXPRESSED ABOUT THE
NURSING HOME BY SPECIFIC RESPONDENT

Dislikes	Respondents			
	Resident (N=14)	%	Family (N=20)	%
None	5	36	3	15
One or more	9	64	17	85
Two or more	6	43	9	45
Three or more	1	7	3	21

Residents liked the staff's personality; descriptive words used included "smiling," "friendly," and "kind." However, family members spoke of attitudes more so than personalities. They used words such as "caring," "attentive," "dedicated," "concerned," "capable" and "responsible." Some respondents singled out specific staff members who epitomized the qualities they described. Categories generated from the data and distribution of subject responses are presented in Tables 10 and 11.

Table 10
DISTRIBUTION OF LIKES ABOUT NURSING HOME STAFF EXPRESSED
BY RESIDENTS AND FAMILY MEMBERS

Staff Attribute	N	Respondent	
		Resident (N=14)	Family N=20)
Attitude	12	3	9
Personality	11	8	3
Specific Quality	5	---	5
Availability	3	1	2
Professionalism	2	---	2
Neutral/No Response	11	11	6

NOTE: Some respondents mentioned more than one attribute.

Table 11
PERCENT DISTRIBUTION OF NUMBER OF QUALITIES LIKED ABOUT STAFF
BY SPECIFIC RESPONDENT

Qualities	Respondent			
	Resident (N=14)	%	Family (N=20)	%
None (Neutral)	5	36	6	30
One or More	9	64	14	70
Two or More	3	21	7	35

Questions probing what the resident and her family disliked about the staff elicited responses which were divided into three categories: staffing, quality of care and attitudes. As shown in Table 12, residents expressed most concern over the small number of nursing staff--professional and ancillary, not getting prescribed medication or treatment, and negative attitudes of some staff members. Family members spoke of the low staff-resident ratio in terms of the rapid turnover of staff, particularly the non-professional nurses aides (who were described as "inexperienced"), and its effect on the quality of care. Some families felt that there was not enough attention given to residents' needs, while others thought there was too long a wait before residents received assistance. The distribution of complaints about staff is presented in Table 13.

One family respondent related how a nurse's aide had removed a foley catheter (an indwelling tube placed in the bladder and held in

place by a water filled balloon) from his mother's cancerous bladder without deflating the balloon. His mother hemorrhaged, necessitating hospitalization. Fortunately the bleeding was controlled. However, this family member felt his mother's physical condition had progressively deteriorated since that time.

Table 12
DISTRIBUTION OF COMPLAINTS ABOUT STAFF BY SPECIFIC COMPLAINT
AND RESPONDENT

Complaint	N	Respondent	
		Resident (N=14)	Family (N=20)
STAFFING	25	8	17
1. Rapid turnover	9	1	8
2. Low staff-resident ratio	8	4	4
3. Inexperienced/poor skills	5	1	4
4. Fewer, less qualified scheduled at night	3	2	1
QUALITY OF CARE	21	8	13
1. Not enough attention to needs of residents	10	3	7
2. Prescribed medicine and/or treatment not given	7	3	4
3. Activities of daily living neglected	4	2	2
ATTITUDES	12	7	5
1. Belittle/no understanding of residents	9	5	4
2. Failure to listen to/tell resident about care	3	2	1

Note: Some respondents made more than one complaint.

Table 13
PERCENT DISTRIBUTION OF NUMBER OF COMPLAINTS ABOUT STAFF

Complaint	Respondent			
	Resident (N=14)	%	Family (N=20)	%
None	5	36	8	40
One or more	9	64	12	60
Two or more	7	50	9	45
Three or more	4	29	7	35
Four or more	2	14	4	20

The managerial staff was criticized by some family members for poor control related to loss of belongings, and for operating with a "profit motive" and not paying competitive wages. Some family members expressed the belief that preferential treatment was given to the more affluent residents. The following quote illustrates that belief: "The wealthy always have staff around, always nice and neatly dressed. I've found mom several times wet and smelly . . . never see wealthy in those conditions. Shouldn't be that way." My observations do not support the conclusion that the source of payment for the residents' care (Medicaid versus private funding) influenced the quality of care received.

Residents were asked how they felt about the way the administrator ran the home (see Table 14). Nine of the 14 residents interviewed said they did not know who the administrator was, did not know how to respond, or had no opinion about the administrator. One resident responded by stating the nursing home was guilty of false advertising

when they advertised "tender loving care." Again, the positive responses made by residents tended to express non-specific or personality qualities such as "marvelous," "pleasant," "nice," and "very good." Thirteen family members had positive things to say, using adjectives such as "professional," "organized," "efficient." Four family members indicated they did not know the administrator and had no opinion. Those few family members who responded negatively toward the administrator expressed these feelings: "You can't tell who's in charge," "management has failed," "he doesn't inspire his staff," "he's not trying hard enough [to solve problems]." Whereas 13 family members expressed positive regard toward the way the administrator ran the home, when asked to remark on how the administrator affects what happens at the nursing home, 11 had neutral or no opinion.

Table 14
EXPRESSED EVALUATION OF NURSING HOME ADMINISTRATOR

Valuation	Respondent	
	Resident (N=14)	Family (N=20)
	Management	
Positive	4	13
Negative	1	4
Neutral	9	3
	Influence	
Positive	2	5
Negative	3	4
Neutral	9	11

An inquiry about the director of nursing--how nursing issues are handled, and the director's effect on the home--yielded similar results as those about the administrator. These findings are presented in Table 15. Seven residents and seven family members said they either had not met the nursing director, did not know who the person was, or had no opinion. The five residents and nine family members who responded positively most often said they were pleased and had no complaints. The next most frequent response called the nursing director sincere and concerned for residents. The two residents and four family members who responded negatively felt the nursing director was disorganized and inefficient, scheduled staff poorly and did not have enough influence over what happened at the home. Five of the six negative evaluations of the nursing directors were from the North home, indicating this measure has some reliability. No resident and only five family members felt the director of nursing had influence over what happened at the nursing home. Five out of the six family members of residents who were not interviewed expressed positive valuations of both the administrator and director of nursing. However only three of the six family members felt positive about the influence the administrator and directors of nursing had over what happened at the nursing home. One respondent said "she may leave orders, but they don't get carried out."

We wanted to know if, in the opinion of the respondents, the nursing home rules prevented family members from doing things with or for their loved ones. Of the 34 residents and family members interviewed only three family members expressed problems with the

Table 15
EXPRESSED EVALUATION OF THE DIRECTOR OF NURSING

Valuation	Respondent	
	Residents (N=14)	Family (N=20)
	Management	
Positive	5	9
Negative	2	4
Neutral	7	7
	Influence	
Positive	---	4
Negative	4	6
Neutral	10	9

rules. These problems were: 1) not being able to hang pictures on the wall, 2) not being able to visit before 11:00 o'clock AM, and 3) only being able to have 30 overnight passes for residents in a year. In the opinion of the nursing home respondents, the institutional policies did not interfere with resident-family relations. In fact, in 13 of the twenty cases the nursing home respondent indicated strong agreement with the position that the nursing home policies made it easy for there to be family involvement with their loved ones.

Respondents were asked what they would change about the nursing home if it were in their power. The distribution of suggested changes by category is presented in Table 16. The disparity in responses by residents and family members is markedly evident on this issue.

Table 16
SUGGESTED NURSING HOME CHANGES

Category	Respondent	
	Resident (N=14)	Family (N=20)
Staffing	2	14
Quality of Care	3	8
Managerial	2	2
None	7	4

Proposed changes related to staffing ranged from hiring more staff at competitive wages to increasing staff training and encouraging attitudinal changes in staff. In addition to suggested improvements in the quality of physical care provided, families would improve the quality of care related to socialization and skill maintenance. Half the residents interviewed (n=7) said they would make no changes. Three residents would improve food preparation, and two would make changes related to staffing similar to those that the family members would make. The suggested managerial changes made by residents and family alike addressed improving the organizational structure of the nursing home.

The Placement Decision

Respondents were asked to recall how the idea of moving to or placing their loved one in the nursing home came about--when, the

persons involved, the circumstances, and the possible alternatives considered. The level of resident involvement in decision making as reported by residents (N=14) was:

No involvement	2
Minimum involvement	4
Active involvement	3
Not sure/confused about process	5

Of the five residents who expressed confusion about the process which resulted in their placement in the nursing home, four showed evidence of memory deficits during the interview. Four of these residents thought "maybe" their children were involved but did not recall the placement being discussed with them, and thus they alone took primary responsibility for the decision. One of the five confused residents insisted her family had nothing to do with her being in the home. Given the confusion of these five respondents, however, these data are unreliable.

Seven of the nine remaining residents interviewed were involved, at least at some level, with the decision making about their placement in the nursing home. At a minimum they were told about the plans. Three of the seven had active involvement. One of these three had discussed the possibility of a nursing home in the event of an incapacitating illness a year before she was stricken. The remaining two residents made the decision themselves in consultation with their family, that a

nursing home would be the best place for them. The two residents who indicated they were not involved with the decision making were seriously ill just prior to the nursing home placement, and so were unable to participate in the decision making process. Both residents who actively sought placement in the nursing home were indigent with chronic health deficits. One was blind and recently widowed, the other was partially paralyzed secondary to a stroke. They felt the nursing home would provide the security they sought. "If you get sick in here they put you in the hospital."

The level of participation in and agreement on placement decisions in the 20 cases as reported by family revealed the following:

Resident and family agreed	8
Resident disagreed	3
Resident not consulted	9

In five of the nine cases where residents were not consulted about placement, the resident was mentally incapable of comprehending the significance of the decision. These five were the residents who were not coherent enough to respond meaningfully at interview.

Family members most often indicated the occasion of an accidental fall and/or a negative health change as the point when nursing homes were seriously considered (n=11). Nine residents also reported a recent negative physical health change prior to nursing home placement. The next most frequent response given by family was the residents reduced

capacity to care for their activities of daily living (ADL) (n=6). Three family members identified deteriorating cognitive functioning as the primary reason for the placement decision. In eleven cases, family members considered their elderly relative required 24 hour supervision or care which had become too burdensome for the primary care giver. Twelve residents were considered by their family to be at least partial invalids.

Nursing home respondents agreed with the reports from family as to residents' care needs. While less than 20% of the 20 nursing home residents studied were bedridden at interview, half or more required assistance in bathing (95%), dressing (85%), toileting (65%), and walking (50%). Six of the residents had difficulty with bladder control, and five had problems controlling their bowels. Eating was the ADL which required the least assistance from nursing home staff according to the nursing home respondents.

The primary nursing home decision makers were adult children in 14 of the cases studied. In the remaining six cases, three decision makers were sisters; two were husbands and one a grandson. Decisions were not made independently. Physicians were involved in nine cases; in-laws and other family members in seven cases. In two cases, friends and ministers were consulted.

Very few economic changes just prior to institutionalization were reported by residents; however, they expressed sensitivity for how their age may have other negative effects on the family. The following statements illustrate this point: "I felt like I was imposing;" "I lived

with my daughter. I thought everything was working alright. I was a burden on her;" "They [children] didn't know what to do with me. I had a gastric tube;" "I didn't want to ask [for help] either, because everybody was busy." One resident said coming to the nursing home was a way to "give my family a break."

Adverse changes experienced by residents in circumstances prior to nursing home placement, as perceived by family, included negative health changes in 18 cases, negative economic changes in six cases, and social changes in 17 cases. The social changes which occurred included changes in living arrangements in nine cases, deaths of significant others in four cases, and relationship changes with significant others in four cases.

Activities engaged in by residents and family members which acted to delay or provide an alternative to institutionalization were: 1) having the aged family member live with the primary care giver (n=6), 2) hiring help (n=6), and 3) using community assistance programs, such as the Upjohn nursing agency and the meals-on-wheels program of the Older American Council (n=3). Eight families said they had not considered alternatives; two families considered other options but decided they were unacceptable.

Difficulty getting about, and difficulty in taking care of their own activities of daily living were identified by residents as the most problematic areas prior to nursing home placement (n=7). Family members identified the 24 hour care needs and their inability to adequately care for those needs as the major problem (n=14). Seven families spoke of

the emotional stress the family was experiencing as a result of trying to care for the resident at home.

The responses shown in Table 17 were given to an inquiry concerning the most difficult thing about the aged family member's care just prior to placement. Six residents said they did not know of any problems or felt there definitely were no problems. The instrumental problems referred to by residents were those of finances and getting shopping done.

Table 17
MOST DIFFICULT ABOUT CARE PRIOR TO PLACEMENT

Problem	Respondent	
	Residents (N=14)	Family (N=20)
None	6	4
Physical care	4	10
Emotional stress	2	6
Instrumental needs	2	---

In ten cases family members viewed the level of care required as the one most difficult thing about caring for their aged loved ones just before placement. Three related care issues specifically to incontinence. But it was to the constancy of care needs, 24 hours a day, to which seven of the families referred. Six family members spoke of the emotional dimension as being most problematic. One son related

the physical and emotional difficulties he experienced from having to diaper his mother. These families expressed emotional pain at seeing their once strong and self-sufficient family member losing independence and facing the possibility of chronic sick role encumbancy. Managing senility and not being able to satisfy their aged loved ones' emotional needs became emotionally stressful for the family care givers. The four family members who identified no problems prior to placement had aged loved ones who lived independently prior to an illness which resulted in hospitalization and subsequent placement in the nursing home.

The residents usually identified their families rather than non-family members as the persons most helpful to them during the time decisions about nursing homes were being made. Key family members also identified other family members as being most helpful during that time. Families also identified other persons/things as being equally helpful. Five family respondents spoke of physicians and nurses, nine spoke of other helping professionals--pastor, social worker, HRS staff person. Finally, four family members cited faith, prayer, and their aged loved one's acceptance of the idea as being most helpful in the decision to place their elderly family member in the institution.

Most residents and their families experienced a number of emotional feelings at placement. As shown in Table 18, residents and family members tended to feel different levels of these emotions. Half or more of the residents interviewed admitted to feelings of depression and helplessness. Only three expressed relief at placement, and these were the residents who actively sought nursing home placement. By contrast,

14 of the 20 family members felt relief at placement. However, an equal number of family members felt a sense of regret. Over half of the family respondents felt guilty. Guilt was manifested in the continuing sense of discomfort about the placement which respondents expressed during interview. For instance, one husband who was married to his wife (the resident) forty-five years and had five children with her,

Table 18
RANK ORDER OF EMOTIONS FELT AT PLACEMENT

Rank	Emotions			
	Resident (N=14)		Family (N=20)	
		N		N
1	Depression	8	Relief	14
2	Helplessness	7	Regret	14
3	Hopelessness	5	Guilt	11
4	Abandonment	4	Failure	5
5	Relief	3	Helplessness	5
6	Anger	2	Hopelessness	3
7	---	---	Depression	1

expressed feelings of both guilt and failure. Visibly upset and close to tears, he said: "I'm still upset and guilty. The upset gets worse not better. I failed in that I had to take her someplace. Makes me sick that I can't take care of her."

The possibility of the presence of any of the emotions listed in Table 18 was specifically assessed in the interview. Subject generated

responses by one resident and twelve family members including the following: "neglect," "upset," "shock," "anxiety," "devastation," "sadness," "disturbed," "hurt-stung," "anguish," "grief," "resentment," "bitter," and "a place to die."

During the interviews the respondents were asked about their present feelings concerning the placement. Half the families (n=10) but only three residents responded in definitely positive terms. One-fourth of the families (n=5) and almost half the residents interviewed (n=6) had definitely negative responses. The five families and five residents who made more neutral responses gave statements such as: "It's alright," "can't do any better," "made up my mind to be satisfied," "[I] needed to be where help's available," "[I] accepted it," "[I] rely on God." The workers in the nursing homes tended to perceive residents and their family members as being more satisfied with and better adjusted to the nursing home than did residents and their family. Nursing home staff respondents felt 14 of the 20 residents studied were satisfied with the nursing home, but could not say whether the remaining six residents were satisfied or not. Table 19 presents a summary of findings from nursing home staff. As can be seen in Table 19, the nursing home staff respondents did not perceive the presence of dissatisfaction in any of the subjects, and out of sixty choices, they indicated "cannot say" in only nine instances.

Twelve of the residents and 16 of the family respondents indicated there was nothing they knew since placement that they wish they had known before. There were also some disagreements that the interviews

uncovered. Residents and family members tended not to agree on issues such as primary reason for placement (28% agreement), what residents attitudes were about nursing homes in general (36% agreement), and the person(s) most influential in making the placement decision (36% agreement).

Table 19
NURSING HOME STAFF PERCEPTIONS OF RESIDENT-FAMILY
SATISFACTION WITH HOME

	Strongly Agree	Agree	Cannot Say	Disagree	Strongly Disagree
Resident is satisfied with nursing home	5	9	6	---	---
Family is satisfied with nursing home	11	7	1	---	---
Resident adjusted well to nursing home	7	12	1	---	---

N=20 cases

Family Association

Eleven residents lived with their primary-care-giver prior to the nursing home placement. Of the seven lucid residents who lived with families prior to placement, five reported regular contact with other family members prior to placement. One had daily phone calls, two

weekly calls, and two monthly calls. Three residents who had close relations living at a far distance from Gainesville reported visits at least once a year. Of the nine residents who were not living with their primary care giver before placement, four also did not live in Florida. Associational patterns reveal that for these four non-Florida subjects there was telephone contact two to three times a week in three cases, and monthly in the fourth case. In this latter case, the resident was working and totally independent until she experienced a cerebral vascular accident (stroke).

Residents interviewed who lived alone in the Gainesville area near their primary care givers (n=5) reported visits from family at least weekly. Except in one case when both resident and family agreed that visits were weekly, family members reported more frequent visits than did their aged relative. Residents and family members agreed on the frequency of phone contacts prior to placement, with these ranging from daily (n=1), two to three times a week (n=2) to weekly (n=1).

Before nursing home placement, the occasions that were reported to bring family members together most often were holidays (n=11), followed by vacations (n=8) and birthdays (n=7). The activities most often engaged in prior to nursing home placement were eating out (n=20), going to church/synagogue together (n=15), going shopping together (n=15), and going on outings (n=14).

In all but three cases, the frequency of contact remained the same or increased after nursing home placement for those nine aged persons not living with the primary care giver before placement. There is 85%

agreement between residents and their family on frequency of contact since placement. Eight of the twenty residents studied were visited by family members daily, seven residents were visited two-three times a week, four were visited weekly, and one monthly. Data on frequency of visits obtained from nursing home staff respondents generally agreed with those provided by residents and their family.

Telephones were not observed in nursing home rooms, and telephone contacts were reported by residents and family in only three cases after placement. However, the nursing home reported higher telephone usage. According to the nursing home staff respondents, one resident talked to family by phone daily, four weekly, three monthly and three rarely. Nine of the twenty resident subjects were reported as never having telephone contact with family members.

Fourteen family members had visited their aged loved ones within 24 hours before the interview; eight on the day of the interview, and six on the day before the interview. Four others had seen their aged loved one within one week, and one within one month.

In answer to the inquiry concerning activities that the residents and family members engage in together now that the aged member was in the nursing home, the most frequent response was being together and talking ($n=30$). Eating out was the next most frequent activity followed by going out for walks or rides, going to church, and going to the family home to visit. Table 20 presents the rank order of shared activities reported by respondents. Other shared activities mentioned

were eating together at the nursing home, praying and sharing religious thoughts, and sharing news and pictures of the family.

Family Exchange

Respondents were asked to think about the helping relationships in their families before and after nursing home placement, the point in time when family members were most helpful, and what sacrifices were

Table 20
RANK ORDER OF MOST FREQUENT RESIDENT-FAMILY ACTIVITIES AFTER
PLACEMENT AS REPORTED BY RESIDENT, FAMILY AND NURSING HOME

Rank	Activity		
	Resident	Family	Nursing Home
1	Conversation	Conversation	Conversation
2	Eating out	Outings/home visits	Eating out
3	Outings/home visits	Eating out	Church/Synagogue
4	Church/synagogue	Physical assistance	Reading
5	Physical assistance	Church/synagogue	Games
6	---	---	Outings/home visits
7	---	---	Shopping

made before and after nursing home placement. I explained that helping included intangibles such as advice, comfort and sharing knowledge. Half (n=7) of the residents interviewed indicated they had given financial help to their families prior to nursing home placement (no controls were placed on the time frame of helping relations). Five

residents reported helping out at home by, for example, preparing meals and running the household. Four residents indicated they did anything for their families that was needed, and three stated they provided child care. Three residents stated their relatives needed no help, so none was given. The helping behaviors cited above are practical and tangible. Residents spoke of non-instrumental helping behaviors on their part in only two cases. Those were providing advice and giving love and devotion.

Nine family respondents indicated they provided whatever was needed for their aged family members prior to placement. When relating helping behaviors, the family's temporal orientation tended to be closer to the actual placement than did residents'. This is an understandable phenomenon given the increasing deficits/losses some residents were experiencing which affected their families during the time immediately before placement. Eight families indicated they provided total care--i.e., fed, bathed, toileted--for their aged loved ones before placement. Six helped out at the resident's home, six did the shopping, and five took care of their aged loved one's business affairs. Other behaviors mentioned were financial assistance, housing and clothing. The emotionally supportive helping behaviors stated to have been given to residents by family members were love and devotion, social involvement and time.

Residents' perceptions of what they received from family before placement included: help at home (n=3), with shopping (n=3), with physical care (n=3), with housing (n=2), and with whatever was needed

(n=2). The instrumental help family members indicated they received from residents prior to nursing home placement were mostly help at home (n=5) and financial assistance (n=3). However, most help family members received from their aged loved ones prior to nursing home placement can be categorized as affectional. Family said they received from their aged loved ones: moral support, love and devotion and encouragement. Also mentioned were reassurance, appreciation, advice, time, and positive response to attention given.

After placement in the nursing home, only three (21%) of the fourteen residents interviewed believed that they had done or were now doing anything for their family. Two residents reported giving their families the use of their home, or deeding the house to them. Three gave their families furniture and household goods. Twelve (60%) of the family members believed that their aged loved ones had provided them with no help since nursing home placement. But eight (40%) of the family members felt they received some form of help from their institutionalized loved ones. They reported receiving reassurance, moral support, strength from the resident's courage, and the satisfactions of "knowing she's there for me," "knowing she's OK," "knowing she's working in therapy" and "knowing she's adjusting to the nursing home."

Looking at what residents felt they were receiving, and what family felt was being given, residents most often reported receiving personal care items (n=5). Four stated their family was taking care of business affairs, and three reported receiving financial assistance. Seven

residents reported family supportive roles of visiting, keeping them in contact with the outside, and assisting them in caring for their plants. However, most family responses related to the provision of physical care to the residents ($n=14$). Some of these services were direct, as in diapering and feeding; others indirect, such as monitoring the resident's care, talking to the physician and getting the staff to give attention to their elderly relatives. Family members reported cleaning dentures, turning down beds at night, and seeing that their aged loved one was toileted and cleaned up for the night. Personal care items were bought, personal laundry done, and business affairs were handled. Family members reported efforts to keep their institutionalized loved ones' spirits up by visiting (weekly or more often in all but two cases), decorating their rooms to the extent permitted, bringing mail, and making regular beauty parlour appointments (both homes had facilities for hair care within the nursing home for those residents unable to go to an outside beauty parlour).

According to the nursing home staff respondents, fourteen of the twenty residents studied provided neither gifts, money, advice, comfort, nor any other help to their family members. They felt the other six residents provided their family with comfort ($n=4$), gifts ($n=2$), and money ($n=2$). Family help to residents as perceived by nursing home staff respondents is presented in Table 21.

Table 21
RANK ORDER OF FAMILY HELP TO RESIDENTS AS PERCEIVED
BY THE NURSING HOME

Rank	N	Family Help to Resident
1	16	Comfort
2	16	Provide personal care items
3	15	Decorate room
4	14	Bring food
5	13	Give gifts
6	11	Advise
7	9	Help with personal care
8	8	Pay medical bills
9	8	Shop
10	4	Pay for nursing home stay

Note that this nursing home staff ranking is at odds with family reports of high involvement with physical care of the residents.

The residents were asked to fantasize about what they wished to do for their relatives. If it were in their power, four residents would give their family members money and gifts. Two would repair or give their family a house, two would do "anything" and one would take her son to Europe to visit the rest of the family. If it were in their power, half the family respondents (n=10) would take their loved ones from the nursing home. Six would care for the resident at their own homes, four would restore the resident's health or replace "worn" body parts--e.g., give "new knees." One family member wished the power to live long enough to see that his mother is adequately cared for.

We wanted to know at what time in their lives the family members were most helpful to each other. Four residents and eight family

members stated that their relatives have been equally helpful all their lives. Four residents stated "now" with being in the nursing home as the family members were most helpful. In one of the twenty cases, the resident and her son had been separated when the son, as a baby, had been put up for adoption. The two had been recently reunited, and thus counted since that time as the most helpful. The family was most helpful for one resident when her husband died, for another, when she moved closer in distance to her family members. One resident, whose sister was her primary-care-giver, indicated she received most help from her sister when their parents died. The sister, on the other hand, indicated there was no time when the resident had been helpful to her. Family members of the resident most frequently indicated they were helped most by the resident when they were young adults (n=6) and when they were teenagers (n=3).

Past sacrifices made on behalf of the family member by residents, as reported by residents, were most often related to providing financial help and assisting with the completion of education. Past sacrifices reported by family members were financial (n=5) and those involved with the provision of care to the aged loved one. This includes, for example, giving of time and accommodating life to the needs of the aged relative (n=8). Five residents felt that they had made no past sacrifices for their family, and in seven cases, felt their family had made no past sacrifices for them. In seven cases each, family members felt that they had not, nor had their aged loved ones made past sacrifices for each other.

Eleven of the fourteen residents interviewed felt they were not making any sacrifices for their families at the time of the interview. However, one resident felt she was making a sacrifice by not asking to go home. In three cases, residents felt family members were not making sacrifices on their behalf. Of those residents who thought family members were making sacrifices, the most frequent sacrifices involved the time, cost, and distance travelled in visiting (n=5). Other sacrifices that residents felt their family was making for them were related to finances and caring for the resident's business affairs.

Nineteen of the 20 family members felt the residents had made no sacrifices since placement in the nursing home. However, the twentieth family respondent felt it was a sacrifice for his aged loved one to be in the nursing home and not ask to go home. Eleven of the family respondents also considered what they were currently doing for their elderly loved ones was not a sacrifice. Those nine family members who did feel sacrifices were being made agreed with residents in reporting cost, distance and time spent visiting as a sacrifice (n=5). Other sacrifices mentioned were: "not doing what I want to do" and "staying in town."

Family Sense of Duty

The key family member and the residents were also asked about their reasons for wanting to keep in touch, and their feelings about concerns and responsibility toward other family members. Ten of the fourteen residents interviewed said love for their family was the one reason

which made them want to stay in touch. Other reasons given by residents were: concern for family welfare, dependence on family as a source of strength, and family as a source of continuity to life.

Nine family members expressed love as the reason they wished to stay in touch. But five felt obligated or bound by duty. Two said they were geographically the closest family members. Other responses included: "tradition/family oriented," to "give joy and contentment," the "need to know about my past," "no reason [I] shouldn't be involved" and because the resident "depends on" the family. These findings are presented in Table 22.

Table 22
REASONS FOR KEEPING INVOLVED WITH FAMILY MEMBERS

Reason	Respondents	
	Resident (N=14)	Family (N=20)
Love	10	9
Obligation	---	5
She's mom	---	4
Residence dependence	2	1
Closest in distance	---	2
Concern	1	1
Continuity to life	1	1

NOTE: Some respondents gave more than one response

Eight residents and sixteen family members said emphatically "yes, family members should be concerned about each other." The other ten respondents had varying degrees of reservations: e.g., "if convenient," "when asked only," the person must "tell what they want family involved with," "if made aware of need" and "strike a happy medium." One

resident and one family member stated family members should not be concerned about each others affairs.

A related question asked about kinds of responsibility family members should take for each other. Table 23 summarizes these responses. Although the question was a general one, as expected, respondents tended to personalize it to the situation of nursing home placement. Answers reflected feelings about their own family members who were not sharing responsibility for the resident. Three residents and four family members thought that families should actively help each other. One resident and four family members said all should share responsibility. Three residents and four family members said family should do what they can. Four family members said one should do anything necessary. Other responses included: "depends on the circumstances," "according to the individual," "when in real need," "be supportive" and "only as the need is made known."

Table 23
RESPONSIBILITY FAMILY MEMBERS SHOULD TAKE FOR EACH OTHER

Main responses	Respondent	
	Resident (N=14)	Family (N=20)
Ought to help	3	4
Do what one can	3	4
All should share responsibility	1	4
Do anything necessary	---	4
According to circumstances/need	2	3
No opinion	5	2

Affectional Feelings

Questions intended to examine affectional feelings of family members asked about communication between family members, sense of closeness, and feelings for family members. First we wanted to know how well residents and their family members could exchange ideas. Table 24 shows that less than half of the resident respondents considered the quality of communications with relatives was positive. Six residents and twelve family members felt they had open and honest communications. Four family members gave responses which can be designated "protective" communication. These family members avoided telling residents upsetting things, were selective about what was discussed, and only spoke of positive issues. Four residents and four family members reported poor communications as evidenced by feelings that they: "never discussed important issues," "never really talked" and "don't listen to each other." Four residents gave responses which can be considered compliant. Examples are: "I don't have ideas," "I can't think," "I never thought about it" and "I depend on and trust (key family member) completely." There was only 43% agreement between residents and family members as to how well they communicated.

When asked about major areas of agreement and disagreement in opinions, six residents and twelve family members felt there were no such areas. Three residents and six family members said there was agreement on almost everything. Two residents felt that family tried to spare their feelings. Three family members indicated they did not

Table 24
EXCHANGE OF IDEAS AMONG FAMILY MEMBERS

Quality	Respondent	
	Resident (N=14)	Family (N=20)
Positive	6	12
Negative	4	4
Protective	---	4
Compliant	4	---

bother residents with problems. One family member explained his approach this way: "I rely on emotions rather than logic." On the other hand, three residents indicated they did not tell family members everything, and did not let them know when they disagreed with them. When residents and family agreed, it was in the areas of the resident's health care needs, social issues and life styles. Disagreements acknowledged were in the areas of family actions and decisions, and issues such as politics and race relations.

Residents most often expressed concern that family members did not work too hard, and had the help they needed (n=5). Four residents expressed concern for the health of their family members. Three residents expressed generalized worry, but were not able to specify what their worry was. Other concerns expressed by residents were for finances. One resident worried that her family members should "find their place in society."

Seventeen family members expressed health related concerns for their institutionalized loved ones. Specific concerns ranged from one family respondent who wished his aged loved one to live as long as possible, to the family member who worried that her aged loved one would "live too long." There was concern expressed that residents were "helpless" and at the mercy of others, that residents not suffer, and concern for watching their aged loved ones deteriorate physically and mentally. For instance, this is how one respondent stated her fears: "she's [her mother] going to get worse. I don't see a very bright future for her. What she's going through, I'm going through." Six family members expressed concern that residents be happy, content and satisfied at the nursing home. Distress was expressed about having no control to make the resident happy, and knowing that the aged loved one would not get out of the nursing home alive. One family member expressed concern over his wife's increasing agitation and his related helplessness to do anything about it. This respondent was also pained by the loss of the physical closeness of his wife.

Eight residents and twelve family members reported seeing or hearing from each other as often as they would like. Six residents and family members each said that they did not. Examination of the data revealed that there was only 28% agreement about the salience of visiting between residents and family members in the fourteen cases where comparison was possible. In two cases there was agreement that family and the resident saw/heard enough from each other, and in two cases there was agreement that they did not. In four cases, residents

did not see/hear enough of their families, but families reported seeing enough of them. In four cases residents saw enough of family members but family members did not see enough of the residents. In two cases, residents felt they were seeing enough of their families, but their families felt they were seeing too much of the residents. Family members of the six residents in the study who were not interviewed indicated they saw enough of their relatives. All of these family members visited their loved ones daily.

The things affecting the frequency of contact were most often reported to be distance, time constraints, and other family obligations of key family members. One family member spoke of how the difficulty he experienced seeing his loved one in the situation negatively affected how often he visited.

Three residents and seven family members indicated theirs had been a continuous close relationship among family. Of the others, five residents reported feeling more close to family at the time of death of their spouse or parents. The remaining six residents who were interviewed related feelings of closeness to events and places such as "when my child was born," "when I was ill," "when I became dependent," and "while in church."

Of the thirteen family members who did not say there were always close relations in their family, four reported feeling most close at the present time. Two reported they felt closest to their loved ones at the time of placement. Two family members felt closest to their loved ones when they were younger than 21 years old. Serious illness, death and

marriage brought three families closer. Finding his real mother after being adopted brought one family closer. However, one family member reported never having had feelings of closeness toward her mother.

Ten residents and eleven family members reported no recent changes in their sense of family closeness. One resident felt a negative relationship change, and one a positive relationship change before placement. One resident reported a negative relationship change with placement, and one resident felt that after placement her family had less responsibility for her, which brought them closer. Of the nine family members who reported changes in relationships, two occurred before placement, five with placement and two after placement. Before placement one family member felt closer to her aged loved one because of her helplessness and dependence. Another family member experienced a negative change which was described as an increase in ambivalence as the aged loved one's demands increased. Four family members felt closer to their aged loved one at the time of placement because of pity and the helpless dependence of the resident. One family member reported a negative relationship change related to the lack of privacy at the nursing home which did not permit the level of intimacy he desired.

At the time of interview, eleven residents and fourteen family members reported a sense of closeness in which they felt happy and good about the relationship. The three other residents interviewed indicated they felt comfortable, good, or nice about their family relations, but not close. Four family members also reported lukewarm feelings toward their institutionalized family member. Relations were "good" and

"nice," but not close. Two family members expressed fairly negative responses. One said the relationship was "frustrating," the other said the closeness between them was "out of necessity." The resident's physical condition and dependence were the factors reported as having most affected positive relations between family and their aged loved ones. Relations were reported to have been affected negatively by the nursing home environment, misunderstandings between the resident and the family, and geographical distance of family members. One family member spoke of her institutionalized mother's selfishness and capacity for only mundane conversation as negatively affecting their relations.

Residents and family members were given five words which identify feelings people might have for each other. They were asked to respond to what the word meant to their family relations. The words were: trust, fairness, respect, understanding and affection. All respondents, except one family member, said they shared trust. Eleven residents and seventeen family members felt there was fairness in their relationship. Three residents felt their family treated them unfairly, and three family members felt their aged relatives were unfair. Twelve residents and eighteen family members felt respect was shared in their relationship. Fifteen family members felt their aged relatives understood them, but only half the residents interviewed ($n=7$) felt they were understood by their family members. All respondents, except two family members, felt affection was shared by the resident and the key family member. One family member indicated that her aged mother was not

an affectionate person. The other family member related her response more to her own feelings saying, "I wonder if I feel close to anyone."

Overall, eighteen of the twenty key family members expressed close feelings which kept them involved with their institutionalized elderly. The other two key family members indicated they felt they must care for their aged relative out of a sense of duty.

Having presented the data obtained in the interviews, we now turn our attention to discussing the findings and conclusions. It is here that illustrating vignettes drawn from the content of subjects' responses will be liberally used to provide richness and depth of meaning to the findings already presented.

CHAPTER 5 DISCUSSION AND CONCLUSION

Summary of Results

Data from this study indicate that family members make decisions to place their elderly loved ones in institutions in a context of love and concern, and most often after trying alternative means to avoid or delay the placement. Family members brought their elderly loved ones to live with them. They hired help to assist with their care, and they engaged community assistance programs for nursing and nutritional support. This finding supports the work of Brody (1977), Hatch and Franklen (1984) and Shanas (1979).

Decisions for placement are based on the needs of the elderly as perceived by their family members and the involved health care provider as well as the set of circumstances peculiar to the particular family. Negative health changes just prior to the placement decision were reported in 18 of the 20 cases. Social changes, including relationship changes with significant others were reported in 17 of the 20 cases. Tobin and Lieberman (1976) found adverse changes in relationships was the single largest difference between their sample of elderly in the community and their sample of elderly on an institutional waiting list. The social changes identified in this study include changes in living arrangements, deaths of significant others, as well as both positive and negative relationship changes.

The social changes identified increased the involvement, referred to as "rejoining" by Steinman (1979), of the family and its elderly members. Rejoining represents a transition in family structure and relationships which demand varying degrees of modification and flexibility. This study supports the conflict model as presented in the literature by Brody and Spark (1966), Bengtson (1979), and Steinman (1979), which views the interactions inherent in the rejoining process as problematic, tending to bring new conflicts, renew old conflicts, and/or continued unresolved conflicts.

Our discussion will illustrate problematic categories in intergenerational interaction suggested in the literature by providing subject generated vignettes which speak to issues of independence vs. dependence, acceptance vs. rejection, continuity vs. disruption, role transitions and equitable exchange.

Precursors to Placement

The feelings and wishes of the elderly persons themselves in regard to the nursing home were not major considerations for the key family members in this sample. Only three (15%) of the twenty elderly family members who were placed actively participated in the decision making. Of the remaining 17 elderly subjects, the mental faculties of five had deteriorated to such an extent that they were incapable of participating in the decision making process. Assuming these five residents would have participated in the decision making if they were capable of doing so, still only 40% of the resident sample would have actively

participated in the decision to place in an institution. This finding is consistent with a study by York and Calsyn (1977) on family involvement in nursing homes which reported only 19% of the residents in their study were involved in placement decisions. In our study the remaining residents were at least aware of plans for institutional placement. However, the low level of agreement between the elderly person who was placed and the key family member on issues of reasons for placement and the elderly family member's attitude about nursing homes suggests that families make assumptions about their elderly family members which they fail to validate. Family members are generally uncomfortable discussing these issues with their elderly loved ones; and the elderly family member, because of her dependent status in the family, does not seek to initiate discussion. Instead she tends to acquiesce based on her perceptions of reduced personal value, her fear of being a burden on the family, and her inability to make equitable exchanges. One resident stated:

I felt bad when people were so good with me and I couldn't do something for them again.

It is not surprising that the elderly have misperceptions about their family's motives, and seek reasons to justify their placement. The following vignettes reflect this tendency of residents to rationalize their institutionalization and to deal with issues of acceptance-rejection and independence-dependence.

A resident with a gastrostomy tube (tube placed in stomach through abdominal wall for feeding) said of her family, "They didn't know what to do with me."

Another resident chose not to ask her family about things which affected her "because everybody's busy."

One resident simply said "They don't want me."

Deteriorating physical health requiring a high level of skilled care, incontinence, or increasing mental confusion involving agitation and wandering behavior are situations with which families feel least able to cope. Yet some family members resist the idea of nursing home placement to such a degree that their own family life, health, or both are put in jeopardy. The following vignette illustrating this point supports Butler's (1979) observation that many families endure enormous hardships to maintain their elderly relatives in the community.

Mrs. A. A. lived alone and remained independent until she was 86 years old. After the death of her older sister she became progressively more forgetful and confused as evidenced by her leaving the gas stove on for extended periods. Concerned for her mother's safety, her 58 year old daughter took her into her home. Mrs. A. A.'s confusion worsened, wandering behaviors began, and she lost all bladder control. A. A.'s daughter could not afford help, so quit her job to devote her time to caring for her mother. The daughter soon found that her mother needed constant attention to keep her safe. The daughter lost sleep--"I got up and checked her [mother] all during the night"--exhausted himself, and became physically ill because of the constant demands involved in the care of her mother. The nursing home placement decision was reluctantly made only after the daughter experienced health failure. The daughter considered it the hardest decision she ever made. "It was like I was turning my back on her. Like someone had died."

One issue which emerges repeatedly is the constancy of care needs; that constancy which requires someone to be alert and responsive to the elderly family member 24 hours a day. Even when financial resources are

adequate to hire help, our data indicate one must be concerned with the reliability of that help and the effects on family life of the presence of a non-family person. There is a struggle for the family to maintain normalcy, to minimize the disruptive forces, to manage the role reversal which now casts the elderly as the receiver of care. The following vignette illustrates one subject's experience of family tension and conflict surrounding efforts to avoid institutionalization of her mother.

Mrs. B. B.'s daughter took her into her home after a progressive deterioration in her mother's health. Shifts of people were hired to come into the home and assist with Mrs. B. B.'s care. The hired help often quit without notice. Quitting without notice created a major problem as Mrs. B. B. would not allow her retired son-in-law to toilet her. Even when a reliable person was found to come in daily, the family's privacy was compromised; "You are almost entertaining." Family time management revolved around the need to relieve the hired help. The daughter expressed these feelings: "There was never a break, never a day off. I was worn out from work and couldn't rest at home."

The Placement Crisis

Each family has its own unique story about the circumstances and events surrounding the decision to place, and the actual placement of their elderly relatives in a nursing home. It is a time of crisis characterized by stressful and conflicting feelings. Our data indicate that placement of a loved one in a nursing home tends to be most emotionally traumatic at the time of placement for those family members who are vested in a position which refuses to acknowledge the possibility of a nursing home until the reality of the need is thrust

upon them. Accounts from family members who experienced strong guilt feelings illustrate the emotional anguish and turmoil surrounding the issues of placing elderly loved ones in institutions. Some family members are able to resolve their sense of guilt in the weeks following placement through the relief of knowing their loved ones are cared for. But for others the knowledge that their elderly loved ones are cared for provides little comfort. The following statements of family members are cases in point.

"We decided we would not send mother to a nursing home, then found out we couldn't do it [take care of her]. [It's] mostly the guilt that we had made a pact to ourselves. We consider ourselves pretty sophisticated and intelligent and able to do those things. We found out it was more than we could handle."--son

"No way do I feel relief. I'm still upset and guilty that I had to take her some place. Makes me sick that I can't take care of her. The upset gets worst, not better."--husband, close to tears

"I feel very guilty. It's disturbing. I'm still constantly thinking how to handle. I want to do something. Don't know what. I sometimes feel close to relief. Then a problem at the nursing home brings down my confidence."--son

"I didn't feel she needed to be there [nursing home]. I cried everyday for two weeks. I still wish she were home. I miss her being there. I will take her home if things don't go right at the nursing home."--son

"Guilt is ingrained because of traditional beliefs. I've heard 'don't send your mother to a nursing home if you love her. They are horrible places'."--son

"I still feel guilty. I had to go to court to commit my father to a mental institution. I declared I wouldn't do it again."--daughter

"I feel guilty. I still go through difficult times--to realize that this [the nursing home] is where she is most well off."--daughter

"I'm guilty still. Everyday. When I don't get there [to visit]. At having to leave her there. I feel helpless. I don't know what will happen. She's not getting better. She's not going to. She's scared to death. I regret she kept living."
--daughter of a stroke victim

Regret and relief are the two emotions which most often coexist in family members who make placement decisions for their elderly loved ones. There is regret that the family was unable to identify a viable alternative; and relief that there is 24 hour care provided their elderly loved ones. This sense of relief reflects the reduction in stress which accompanies 24 hour responsibility for the care of a dependent elderly loved one, plus the reduction in family tensions which tended to increase over time as the family made adjustments to accommodate the needs of their dependent elderly family member. Other powerful emotional feelings are experienced by the family decision maker, notably those of guilt, failure, helplessness and hopelessness.

While regret and relief are the feelings most often experienced by the primary decision makers, elderly persons being placed in institutions most often feel depression and helplessness. Their dependence on others to assist them with the very basic activities of daily living makes them vulnerable. We know from the literature (Sanders and Seelback, 1982; Shanas, 1979) that family members are the preferred caregivers for the elderly. Institutionalization has the effect of reducing informal family caregiving activity, and forces the elderly resident to rely on the resources available in the often

impersonal institution. Depression and helplessness are responses to the elderly resident's power position. Independence is further eroded as autonomous behavior is severely restricted, being mediated not only by physical and cognitive limitations, but also by necessary schedules and policies which keep the institution functional. Residents with physical limitations which restrict their ability to care for their personal needs are particularly at risk from those staff who regrettably lack the compassion and/or skills to protect the health, dignity and integrity of the elderly entrusted to their care.

Attitudes and behaviors of caretakers can be distressing and demoralizing as illustrated by the report of this partially paralyzed resident:

"Some nurses talk so hateful to you sometimes. One told me I could turn over if I wanted to. I couldn't turn over if the house was on fire."

Another partially paralyzed resident related her feelings of humiliation when a nurse refused to insert a urethral suppository (medicine for insertion directly into the opening leading to the bladder).

"[She] make me feel like two cents. Made me feel worse than dirty."

For the elderly person who has moderate mental deficits, failure of the staff to clearly communicate their intent tends to intensify existing mental confusions. Resident M. said of her experience in the nursing home:

"I'm confused about what goes on. People do things without asking me. People decide things without asking me."

Fear is evident in residents who display mental deficits, but who maintain a tenuous contact with their surroundings. There is present a generalized feeling of uncertainty and a sense that things that go wrong may be their fault. Their perceptual deficits interfere with their ability to accurately interpret the environment, thus creating a sense of constant threat. Residents in this category expressed acute concern about confidentiality during interview. They were afraid that relating their thoughts and feelings about the nursing home would somehow get them in trouble.

Adjustment to Placement

At the time of interview the residents had resided in the nursing home an average of six months, yet only three of the fourteen residents interviewed had definite positive feelings about being in a nursing home. Adaptive mechanisms used by some residents were those of resignation and acceptance of their fate. The following statements by nursing home residents are enlightening:

"I made up my mind to be satisfied with what happens."

"It's a have to case [living in nursing home]. I don't think anybody will feel good about being in a place like this."

and

"[I] made up my mind this would be it. Let the Lord take care of me. Do what He wanted with me."

Adjustment for some residents is more traumatic. There are those who actively resist the facts of their situation, sometimes projecting their anger and frustrations toward their families.

"She [daughter] told me, 'momma, I'm not going to let you go to a nurses' home'. I thought that was settled. I've been living in hell since I've been here. [My] daughter tells me things I don't believe. I won't live six months. Just as well have someone dig my grave."

Others despair or wish for death.

"I wish everyday the Lord would see fit to come and take me. I wish I could die. I'm prepared to go."

"I hate it [the nursing home]. I don't like being a cripple. I'm not ready. But no one can do anything."

The nursing home placement decision was a last resort choice for most families. If given the resources to manage the psychological and physical deficits of their elderly loved ones, the majority of the family members interviewed would prefer to take their loved ones from the nursing home. Nursing homes as institutions, even when newly opened and with pleasant physical environment, are not accepted as preferred solutions for dependent elderly loved ones if families feel there are other viable alternatives which meet their particular requirements. Financial support, transportation, counseling programs for elderly and their families, home care nursing, elderly day care centers, supervised living arrangements and provision for meals and housekeeping services are some of the community based programs often identified in the literature which would tend to delay institutionalization if they were available and if they were found acceptable by the family decision

maker. However, Sargl (1985) makes the point that while these services can reduce stress on the caregiver, there is no clear indication that services to the family will reduce or delay institutionalization.

Family Involvement with Residents

The frequency of contact between family members and their elderly loved ones increases or remains the same after nursing home placement for those elderly who did not live with family members prior to placement. As expected, for those elderly persons who lived with family, the frequency of contact with family members is lower. Visiting and conversing is the top ranked activity engaged in by family and residents; it was reported by all respondents. Conversing is the one activity in which most residents can participate without there being excessive demands made upon them. Eating at a place away from the nursing home and going on outings are the second and third ranked activities. These three activities, conversing, eating out, and going on outings, are all time-occupying devices which can be viewed as the family's means of expressing continuing caring, love and devotion for its elderly member, while at the same time providing social stimulation and contact with the world outside the confines of the nursing home. For some residents and their family members, regular attendance at their church or synagogue is an important source of spiritual strength.

It is interesting to note that except in a few instances, neither residents nor their family members feel the institutional rules interfere with their doing things for and with each other. But even

when institutions make every effort to be considerate and accommodating, there is a loss of a certain amount of privacy and freedom which acts to alter the dynamics of the family relationship. One family member related how the nursing home placement had negatively affected the feelings of closeness he felt toward his mother. Lines of communication deteriorated as his mother is bedridden and no telephones are in residents' rooms. Because his mother has a roommate, visits lack the privacy which they had come to enjoy when she lived independently in her apartment. At the nursing home this family member's relationship with his mother is "not as close simply because of the surroundings. There is not the intimacy to sit quietly and talk."

A bureaucratic system in the guise of a nursing home has intervened to assume major responsibility for a family member which once belonged exclusively to the family. The reduction in privacy and the requirement to conform to institutional rules and regulations for visiting, personal space, personal objects and outside access are some of the costs families experience in exchange for the assurance of around the clock attention to their aged loved ones.

Sussman (1977) has suggested that family members can positively influence the care provided their institutionalized elderly loved ones by getting involved with the caretakers. Our findings indicate that most families do not exercise their right to get involved with the institution. They are most often unaware of who the administrator and director of nursing of the home are, and even less aware of the roles and influences of these key actors. Of particular interest is the

finding that those families who are actively involved with the institutional staff on behalf of their loved ones are most often the family members of those elderly persons who are emotionally withdrawn and unable to effectively relate their needs and desires. These family members spend longer periods of time at the nursing home and take a more active role in the care of their elderly loved ones than do family members of the residents who are able to verbalize their needs. By limiting their involvement, family members miss a valuable opportunity to act on behalf of their elderly loved ones. All the issues of concern identified, including those of staffing, quality of care, and staff attitudes, can be appropriately addressed through involvement with the institution's nursing and administrative staff. Yet it sometimes happens that the family member acts super-reasonable and understandingly, even when an act of omission or commission seriously jeopardizes the safety of the elder person. Such is the case of the family member who reported the injury to his mother's cancerous urinary tract system which was inflicted by a nurse's aide who improperly removed the catheter.

Observations and analysis of interview data support the identification of three general levels of family involvement with their institutionalized elderly for those families who maintain regular and frequent contact. For simplification these levels of involvement have been designated detached, involved, and committed. Descriptions characteristic of each level of involvement follow.

The detached family

This family is attentive and provides for their elderly loved one's instrumental needs, but is emotionally detached, acting primarily out of a sense of duty, showing no real depth of feeling. The nursing home placement is not very traumatic for this family member. It is accepted as a part of the normal course of events which takes place at a given point in one's life; a normative process. There is little awareness evident of the elderly family member's pain.

Resident C. C. lived alone in a retirement apartment complex until her progressively failing health resulted in her sister, on the advice of the physician, arranging nursing home placement. C. C., never married, devoted her attention to the care of her aging parents until their deaths, after which she lived a reclusive existence. The sister is opposite to C. C. in temperament and actions. She is a retired school teacher, is married to a physician, and has an active social life. The difficulty C. C.'s sister experienced at placement were related to the "physical business of going through everything to make sure she [C. C.] didn't have bills that needed attending to." Relief that someone professional is on call 24 hours a day is the only feeling the sister acknowledges. "[I] relaxed and didn't worry anymore." C. C.'s sister visits her and provides for her instrumental needs, but is not really involved with her. C. C. cries and says, "I'm not too happy now. Guess I will stay here until I die."

The detached family member cannot be faulted for lack of a sense of duty; however, there is not a strong sense of closeness. Conflicts which may exist tend to be latent. Perhaps the emotional detachment and low sense of closeness preclude open and active conflict between the resident and the family member.

The vignette makes clear the idea that resentment and acceptance vs. rejection are important issues with which residents in nursing homes are confronted.

The involved family

This family is emotionally involved with their institutionalized elderly. Emotional and affective needs as well as instrumental needs are addressed as behaviors are directed toward cheering and comforting the resident. This active involvement with the concerns of the elderly loved ones can also tend to potentiate any existing latent conflicts. Perceptions by the family of excessive demands being made upon them by the elderly, or perceptions of the elderly that they are being neglected by their family create active conflicts which most often are not dealt with directly. The following are examples of family reactions to perceived demands:

A son said of his relationship with his 95 year old mother: "I regulated my entire life around her wishes. I put her above my wife. A mistake. There's no problem if [the elderly] is independent. A problem when they need constant attention. Whoever's at home takes the strain. My wife was under strain."

A daughter about her mother: "She's totally dependent on me for visits. That's a heavy burden. My kids are not as dependent as she. I try to think how it would be if I was sitting there day after day and she was the only one coming to see me. She's just a part of my life whereas, right now, I'm all of her life."

A daughter expressing frustrations at her mother's demands: "She irritates me with her constant complaints. You'd think she would realize all the problems I'm having and appreciate that I'm coming [to visit]."

The following are some expressions of perceived neglect voiced by residents of involved family members:

"I don't want to be a bother. I can imagine how it is. You know how young people are. They don't want to have any trouble with old people. Especially sick people that are handicapped. They have to do what they want to do. They are young."

and

"I'm just worrying. I won't be so worried if I'm home. I don't want my daughter to get mad with me. But she's already paying, why can't she pay for someone to care for me at home? I don't want to live like this."

The above vignettes provide illustrations of the same struggles within families of the institutionalized elderly as those identified in the literature by Bengtson (1979) and Steinmen (1979) as occurring with increased involvement of children with aging parents. Continuity vs. disruption, role transition, acceptance vs. rejection, independence vs. dependence are all issues that arise in residents and their families. Whether the conflicts are old, continuing or new, they tend to become sources of anguish for both the resident and the family members. Conflict notwithstanding, the family and resident remain closely involved, providing for affective as well as instrumental needs. This higher level of involvement than is evident with the "detached" family places the involved family at risk for activating

unresolved, latent conflicts from an earlier period in the family's life cycle, and at risk for the development of new conflicts.

The committed family

The committed family shares with the detached and involved families the qualities of providing instrumental and affective needs for their elderly loved ones. It differs in that the committed family member also gets actively involved in the physical care of the resident, has a higher level of emotional involvement, spends extended periods of time with the elderly loved one at the nursing home, and closely monitors the staff actions directed to the care of the elderly loved ones. The families of most of the six residents who were unable to cooperate with the interview fall within this category. The families appear to recognize the special vulnerability of these residents due to their inability to effectively communicate. And so families act to provide the protection that comes with high visibility and active participation in the care of their elderly loved ones. Deteriorated mental and physical conditions do not diminish involvement of the committed family. The following statement of a family member captures this feeling:

"I just love her like always. Her condition hasn't changed anything one bit. Never would."

Whatever conflicts are present in the relationships of the committed family remain latent. Energies are focused on assuring and providing care for their elderly family member.

Interpersonal communications

Elderly residents tend to devalue themselves. They feel they have provided nothing to their families since nursing home placement. The elderly discounts wisdom, the traditional resource which is said only to come with age, when assessing their own selfworth. Instead, those few residents who had material goods indicated they gave them as gifts to the family. The implication is that with the loss of physical stamina, and without material goods, there is nothing else with which to bargain. However, the elderly's attitude as perceived by the family, whether accurately or not, assumes great importance. The more comfortable and accepting the loved ones are of the nursing home, the fewer ambivalent and conflicting emotions are experienced by the family. Thus most residents learn to comply with expectations, to acquiesce, and give the appearance of acceptance.

That there is merely an appearance of acceptance is supported by our data, which indicate that family members and their elderly loved ones do not talk about issues which really matter to them. Family members actively seek to avoid important issues and upsetting issues in their conversations with their elderly loved ones. The elderly are aware of this avoidance behavior by the family. Only 42% of the elderly feel ideas can easily be exchanged as compared to 60% of the family members who feel ideas are readily exchanged.

Thus residents of nursing homes often are made to feel left out of another phase of family interaction when they come to realize that "They don't especially talk to me about important things." Or that what the

elderly person says no longer has importance. For example one resident said of her son, "He doesn't listen to me. He's smarter than I am. He knows more than me."

Cicirelli (1983) notes that adult children tend not to share intimate details of their lives and important decisions with parents, regardless of how close their relationship. It appears that subjects in this study did not talk with each other about important issues affecting them during the periods before nursing homes were considered. Since nursing home decision-making and placement, families have assumed a need to control information in an effort to protect their elderly loved ones. It is perhaps a natural impulse to want to protect a dependent family member, but one wonders whether, in the long run, the constriction of information may prove to create more anxiety than it allays.

Control of apparently upsetting news to protect the elderly who have retained the capacity to reason and communicate would appear to have the potential to impose upon the elderly a form of cognitive isolation. When decisions are made for people without their input, when persons are selectively communicated with about things that matter to them, when emotions without logic form the basis for interactions, then there will continue to be unnecessary misunderstandings within families.

The low level of agreement on the salience of visiting between family members and the elderly loved ones (28%) again emphasizes the divergence in perceptions within families about issues which intimately affect them. Family members do not really know about the psychosocial

pains and sufferings of their elderly loved ones. Conversely, neither do the elderly know how real the hardships are for their loved ones. Distorted perceptions on the part of the actors appear to serve as protection against the overwhelming realities of their situation, and both intrafamilial and intrapsychic conflicts can be kept at manageable levels.

Regardless of the interpersonal conflicts evident in the subjects of this study, with few exceptions, the elderly resident and the family member expressed an enduring sense of closeness toward each other. For elderly residents, love is the prevailing reason for wanting to remain close and in touch with relatives. Love influences the action of family members toward their elderly, but it is the physical and emotional condition and dependence of the aged loved one which are most often cited as evoking feeling of concern, pity, sense of duty and caring behaviors. These emotions and the bond of kinship act to keep family members involved with their institutionalized elderly regardless of their feelings of closeness or the level of enmity.

Theoretical Implications

In this study we have described and analyzed the family relations of the institutionalized elderly. Open-ended interviews were used in order to allow emergence of information which would provide insights into the process of relatedness between the institutionalized elderly and the primary care giver. Grounded theory in the tradition of Glaser and Strauss (1967) informed this study. The study began with an

interview framework which had the flexibility to be modified as data emerged. This approach provided the freedom to be open to and guided by what the subjects had to say. Interviews acquired meaning from the contextual data brought to it by my presence in the nursing homes, by my observations of interactions between family members and their elderly residents, and by my witnessing the responses of both family members and residents to the impact of an intervening bureaucratic system on their lives. It was through these observations along with interview data that allowed comparisons of attitudes and behaviors which resulted in the emergence of the three categories of family involvement with their institutionalized elderly.

The findings support a number of theoretical propositions identified in the literature concerning pre-institutional family relationships. For instance, eleven of the twenty elderly subjects lived alone or with a spouse prior to institutionalization; and of those elderly living with family prior to placement, all but one had made this move in response to negative social changes or failing health. Elderly subjects identified family members as the preferred source of support during times of illness and/or trouble. In addition, regular contact was maintained with at least weekly visits when family lived close by. No subject reported less frequent than a once per month contact. Thus our data are in essential agreement with Rosenmayr's (1977) concept of "intimacy at a distance" and Shanas's (1979) findings on frequency of contact and preference of support.

Rejoining (Steinman, 1979), a time of increased involvement of aged parents and adult children, occurred with our subjects, as did protective and helping behaviors in response to frail and needy elderly family members. These responses of family to their frail elderly can be conceptualized in the framework of attachment theory. Cicirelli (1983:32) refers to attachment as an emotional or affective bond between two people manifested by being identified with, in love with, and having the desire to be with another person. Within this framework, protective, helping or caregiving behaviors observed are viewed as responses to real or implied threats to the elderly family member's continued existence, "which serve to diminish the threat, maintain the survival of the elderly..., and preserve the emotional bond" (Cicirelli, 1983:33).

It cannot be assumed that attachment is equivalent to affectional feelings. Weishaus (1979) cites filial maturity, responsibility, obligations--i.e., duty and family loyalty as factors other than affections which keep family involved with their frail elderly. By virtue of family relatedness and structural suitability (Sussman, 1977; Weishaus, 1979), an emotional bond is created which elicits behaviors in response to perceived threats to family members.

Consistent with the findings of Greene (1982) and Maddox (1975), family resources, structural limitations, and degrees of impairment of the elderly family member are major determinants of decisions to institutionalize. Broad conceptualization of attachment as an emotional, but not necessarily an affectional bond, allows for other

related factors in explaining family involvement with their institutionalized elderly; factors such as duty, loyalty, pity and levels of disability and dependency which were reported by subjects as influencing interaction with and sense of closeness toward their institutionalized elderly family members. The three levels of family involvement with institutionalized family members culled from our data can be viewed in this broad context of attachment theory. Variations across categories in instrumental and affectional support given by the detached, involved, and committed family can be explained in terms of the degree to which there is identification with, love or desire to be with their institutionalized elderly family member.

Issues relative to continuity and disruption, independence and dependence, acceptance and rejection, as well as role transitions and family exchange (Bengtson, 1979; Steinman, 1979) have all been brought to bare on the family system by the very act of institutionalization.

Our data support Shanas's (1962) observation that almost all older people view long-term placement with fear and hostility, and perceive placement as rejection. Depression, helplessness, hopelessness and abandonment are the four highest ranked emotions identified by residents as being experienced at placement. Residents cannot escape what Tobin and Lieberman (1976:216) call the experience of "personal vulnerability" when confronted with the meaning of institutional living.

Bengtson (1979) spoke to the importance of continuity of family identity for those of advancing years, citing geographical mobility, divorce and life style changes as threats to continuity. In this

context, institutionalization of the elderly can only be viewed as a disrupter. The elderly family member is removed from familiar surroundings, often from a household surrounded by close kin, and placed in an unfamiliar setting to which she must successfully adapt if she is to survive. When institutional life begins there is physical and social discontinuity from autonomous community living (Tobin and Lieberman, 1976:233). There is evidence that taking the elderly from familiar surroundings is hazardous and may be a "prelude to death" for many of them (Blenkner, 1965:52).

Incipient changes along the independence-dependence continuum may have been occurring over time, with the elderly depending more and more on family for support. Blenkner (1965:57) argues against the role-reversal concept. Rather, she sees adult children taking on a "filial role, which involves being depended on and therefore being dependable . . . " With institutionalization there is transition into another, often final role for the elderly; a role regulated by institutional rules governing the most basic functions and activities of living, coupled with dependence on strangers to provide the very means for continued existence. The negative emotions elderly subjects report feeling upon placement are precipitated by the upheaval which disrupted their usual way of life. Feelings of abandonment are expressions of perceived rejection by the family.

Upon placement of their elderly in institutions, family members, on the other hand, report equal levels of regret and relief, followed by guilt, an emotion which is consistently seen by other researchers as a

dominant issue between parent and child (Brody and Spark, 1966; Dobrof, 1977; Hirschfield and Dennis, 1979; Schwartz, 1979; Tobin and Lieberman, 1976; Weishaus, 1979). There is relief that the 24-hour a day care needs of the elderly are taken care of, and that there is the availability of immediate medical attention. In addition, relief is experienced from the emotional and physical strains of direct responsibility for constant care needs. Family members reported that physical care and emotional stress were the two most difficult things about care of their elderly loved ones before placement. Regret and guilt can be viewed as responses to institutionalization of the elderly loved one, which symbolizes the failure of family support to that family member (Smith and Bengtson, 1979).

It is in this context of family crisis that Mattson et al. (1978) cite the need to perpetuate and redefine family relations. Redefinition of relatedness presents a challenge to the family, for institutionalization of one of its members tends to accentuate, rather than diminish, the problematic categories and conflicts in intergenerational interaction identified by Bengtson (1979) and Steinman (1979). We found families struggling to redefine their relationships with their institutionalized elderly. Family members were confronted with their own often conflicting feelings of relief, regret and guilt, plus those of their elderly loved ones . . . depression, helplessness, hopelessness and feelings of abandonment.

While family association as measured by frequency of contact generally remained at a constant level of once per week or more, this

frequency of contact appeared not to be an indicator of the quality of the relationship. For instance, those family members categorized as "involved" who spent a great deal of time with their institutionalized elderly, and who provided instrumental and emotional support, also tended to experience the greatest amount of overt conflict. Family attachment is undeniable, yet relationships are strained by reactivated, continuing and/or new conflicts precipitated by placement.

Sussman (1977) and Treas (1979) identified the primary modalities of exchange as visitation, companionship, communication, emotional and social support, financial aid, gifts, child care, advice and counsel. Our data support the idea that after institutionalization, visitation, companionship, emotional and social support continue to be important exchange modalities. Subjects agree that the flow of commodities is unequal, coming overwhelmingly from the family to the resident. However, there is a wide discrepancy in perception about exchange between residents and family members; particularly about the commodities exchanged and communications.

Most residents report family members primarily provide affective assistance, such as visiting and keeping them in contact with the outside. However, family members report that they primarily provide instrumental needs, including direct physical care such as diapering and feeding. As for communications, half of all the residents interviewed expressed the feeling of being misunderstood and/or not listened to by the family members. On the other hand seventy-five percent of family members interviewed felt they communicated effectively with their

institutionalized elderly. Some residents dealt with problems in communicating by giving up on making an effort to have themselves understood. Instead they acquiesce, as if agreeing, accepting or complying with the family's thoughts, feelings, wishes and actions. The effect of this acquiescence is the reduction of overt conflict. Thus there may be the appearance of improved relationships between the resident and family, as is suggested by Smith and Bengtson (1979). Nevertheless, it is questionable whether the acquiescence of one party to a relationship which our data suggests is a true expression of or indication that there has been improvement in the relationship.

Our findings coincide with Smith and Bengtson's (1979) in that our subjects, like theirs, experienced alleviation of acute stress on the family and relief at knowing their loved one's basic needs were provided for. We differ in that our data did not support the idea that institutionalization of elderly relatives strengthened family realtions. Structural, population, and organizational differences in the nursing homes in this study and that of Smith and Bengtson may account for differences in our findings. The subjects in the Smith-Bengtson (1979) study were a homogeneous religious and social class group, in a not-for-profit home, supported by a religious group, with its implied spirituality. In addition, institutional policies actively encouraged family involvement. All of these elements can be viewed as forming necessary conditions in which families are able to grow in cohesiveness and solidarity in spite of the discontinuity caused by institutionalization. On the other hand, a proprietary nursing home

(some subjects expressed feelings that the profit motive was of paramount importance to the management), with a cross-section of religious and class differences among its residents, and without programs specifically designed to encourage meaningful family involvement, as is the case with our study, may tend not to replicate Smith and Bengtson's positive consequences for family relationships. For the most part the proprietary homes studied lacked those socio-psychological elements which are likely to be found in a religious home.

Conclusion

Several findings emerged from this small study which have important implications for persons involved with providing services to the elderly and their families, policy makers, and researchers concerned with the institutionalized elderly. First, it was found that decisions to place elderly family members in institutions are made by a family member in collaboration with other family and caretakers, but most often without the active participation of the person who is affected most. The wishes of the elderly person in regard to placement are not important considerations. In addition, family members make inaccurate assumptions about how the elderly feel about issues which affect them. Nevertheless, it was found that placement decisions were made by family members in the context of love and concern, sometimes after enduring enormous hardships to avoid placement. Our data support those studies which reject the idea that families use nursing homes as dumping grounds for the elderly, but more often as a last resort solution when viable

alternatives for the care of the sick and dependent family members are not available (Brody and Spark, 1966; Treas, 1977). The data permitted generation of typologies which identify three levels of family involvement with their institutionalized elderly based on the nature and quality of the relationship. Families of the elderly in institutions who maintain contact can be categorized as detached, involved or committed. The detached family member does not necessarily neglect the elderly, but has minimal emotional attachment, acting more out of duty and obligation, and caring more for the resident's instrumental needs than affective needs. Conflict tends to be latent. The involved and committed family members differ primarily in the intensity of their relationship with their elderly loved ones. The involved family member provides instrumental and affective needs, visits regularly, but does not spend prolonged periods of time with her institutionalized elderly. There is likely to be open conflict and the visiting family member often feels frustrated and uncomfortable. The committed family member is more extensively involved, provides for both affective and instrumental needs, and tends to subjugate personal needs to the needs of the elderly family member. Family members in this study did not, for the most part, exercise their right to become involved with the institution in such a way as to positively influence the care of their elderly family members. They were largely unaware of who the administrator and director of nursing were and proportionately less aware of their roles and influence. However, the family and their elderly loved ones identified major problematic areas associated with

the nursing home. These are the areas of staffing, particularly the rapid turnover of non-professional staff; quality of care, related to neglect of prescribed treatments and attention to the needs of the residents; and staff attitudes toward the elderly entrusted to their care.

Second, family members continued regular and frequent association with their institutionalized elderly after placement. For those elderly persons who lived alone prior to placement, the frequency of contact tended to increase. The two most frequent activities families engaged in were conversing and eating out. Although conversing is the major activity for residents and their families, our findings indicate they have difficulty communicating openly and honestly. In an effort to protect the elderly, family members actively avoid talking about important issues that affect them. There is a low percentage of agreement between residents and their families on attitudes about the nursing home, placement decisions and circumstances leading to placement and how well they communicate. It appears that family members tend to make assumptions about the feelings and wishes of their elderly loved ones, then make decisions based on those assumptions without checking them out with the elderly person who will be affected. The elderly as a rule defer to the wishes of their families, converse on a superficial level, cease to try to make their concerns known to their families, but instead acquiesce and become compliant.

Third, nursing home placement tended to further erode declining feelings of self-worth. Most residents interviewed felt they had

nothing to give in an exchange relationship with others. While some family members cited characterological qualities as resources for exchange, most family members and residents thought only of material goods as exchange resources. However, the elderly resident's acquiescence and appearance of acceptance of placement acted to reduce the ambivalence and conflict family members experienced as a consequence of placement, and can be viewed as the commodities available to the elderly for exchange. Family members of residents who still actively resisted acceptance of being in the nursing home were found to also have unresolved feelings about the placement. Most family members felt they were making no sacrifices by their involvement with their institution-alized elderly. When respondents felt sacrifices were being made, these were in the form of cost of care, distance travelled in visiting, and time commitment involved which constricted the family member's freedom to get involved with other activities.

Fourth, family members and residents alike felt families have a duty to help out each other when they are in trouble. Love and obligation were the reasons most often mentioned. There is evidence that family are involved with and give assistance to their insitutionalized elderly even if there is not a strong affectional bond, as illustrated with the "detached" family. Some respondents voiced anger towards members of their family who they felt were not fairly sharing the responsibility for their institutionalized family member. This suggests that within families, all three levels of involvement

identified may exist depending on the degree of attachment felt by a particular family member.

Finally, residents and their family members have different perceptions of how important they are to each other. Feelings of closeness were most often reported to be constant over the life span. However, some respondents related an increased sense of closeness to specific times and events, such as births, marriages, deaths, and nursing home placement. Emotional conflicts family members felt were not necessarily resolved as a result of relief from the burden of providing direct care. Nor did we find clear evidence that the nursing home placement improved the quality of family relations as is suggested by Smith and Bengtson (1979). It is possible that our findings differ because of organizational and structural differences in the homes studied. We found that most residents felt misunderstood by their families, and families felt both internal and interfamilial conflicts. These results support the idea that intergenerational rejoining tends to activate latent unresolved family conflicts (Bengtson, 1979; Steinman, 1979), and the concept that family relationships in later life are extensions of previous interactions within the family network (Brubaker, 1985). There is nothing to suggest that this changes with institutionalization.

Implications of study

This study has important implications for applied gerontology. We have found that families remain involved with their elderly relatives after decisions to place and actual placement in institutions. We

attribute this continuing involvement to the emotional bond of attachment, including those sentiments of love, pity, duty and obligation. We have also noted that this continuing involvement after placement in and of itself does not assure the quality of that relationship. Conflicts that tend to come with rejoining are still evident at placement, when they are likely to be exacerbated by added powerful emotions such as feelings of rejection, abandonment and guilt.

Since our population trends indicate increasing numbers of persons 75 years and older, and since the chance of insitutionalization increases with advancing age, it becomes important for families to be equipped to deal with the economic, social and emotional costs associated with long-term institutional care. To this end, we view it as important for helping professionals and institutions that serve the elderly to define not only the elderly, but the family as client. A family perspective can relieve some of the fears, stresses and frustrations the elderly and their families experience, both from the family crisis precipitated by decision making and placement, and also from the strain of dealing with bureaucratic organizations with goals which may not coincide with theirs.

Our finding that the elderly and the family have different perspectives about behaviors, feelings, and events lead us to view communications in particular as a problematic area in which family conflicts are played out, often without mutually satisfying outcomes. Families need support in effectively communicating with their institutionalized elderly in order for both the resident and family

members to reach an understanding of each other's feelings and needs. Consideration must be given to preexisting strains in the family relations which may carry over to the institution. However, with support, families should be able to communicate more effectively and be more responsive to each other's needs. Specific strategies suggest themselves:

1. During the pre-institution decision making, helping professionals who are approached by the family should include the elderly family member in all phases of planning if she is cognitively able to participate. Discussion should be open and honest, should include the pros and cons of possible alternative solutions, and specific reasons why institutionalization appears to be the most viable.
2. In keeping with the concept of the family as client, institutions should develop orientation programs for families. This orientation must not be limited to the organization, structure and rules and regulations. Key personnel need to be identified and their role delineated. Families need to know whom they can relate to, and whom they need to approach with a particular concern and/or problem. Few of our subjects knew who the administrator and the director of nursing were, nor did they know how these persons could influence the care of the resident.
3. We suggest that institutions develop programs designed to inform the family about aging, including common problems

encountered, realistic expectations, and especially effective communication techniques. York and Calsyn (1977) found that families felt a need to be more involved and knowledgeable in their relative's care. Formalized programs were seen as one method of obtaining that goal.

4. Finally, we suggest the organization of groups as a means by which residents and families can be given support in dealing with and resolving the powerful emotional feelings that institutionalization elicits. Several formats are possible; resident groups, family groups, and co-joint groups of family and residents. For those residents who retain cognitive abilities necessary to participate in groups, the latter format presents opportunity for resolutions of long-standing problematic issues within families.

With institutionalization a formal organization, a secondary group, has taken over the role traditionally held by the family, a primary group. It is felt that these institutions have responsibility to meet some needs of the family, just as the family has responsibility to continue to meet some needs of their institutionalized elderly. The strategies suggested would provide education, counselling, and emotional support to assist in coping with the reality of the situation. Family relations with institutionalized elderly would be validated as an extension of previous associations within the family. The importance of continuity of the family will be underscored with opportunity for more

effective communications, mutual understanding and improved affective quality of the relationship between the elderly resident and the family.

Economic Issues and Legislation

We have dealt primarily with the family relations of the institutionalized elderly. However we consider institutional placement as properly a last resort solution to a difficult problem. We have cited the enormous hardship many families endure to avoid placement of their elderly. When families become burdened beyond what their resources can endure, placement occurs. Researchers and helping professionals have proposed services and economic incentives for families to care for their aged. However, there is considerable disagreement as to the nature of the incentives, how they are to be administered, and how abuses can be avoided (Sargl, 1985). The Veterans Administration provides an allowance to low income, aged veterans who need regular assistance, and California is an example of a state which provides a flat sum of money whether home help is purchased or provided by the family (Sargl, 1985).

Sargl (1985) looks at how some other countries address problems of their frail elderly. England and Sweden give pension credits to persons who leave the work force to care for an elderly relative. Low cost loans for renovating or building an addition to a house to provide space for a disabled older relative are provided by Japan, Australia, England and Sweden. But our country has not developed a national policy to address the problems of help for families caring for their frail

elderly. The cost of incentives, which some feel will be astronomical, is a major impediment to appropriate legislation which would define and fund these programs. Further, there is a conflict between states and the federal government over who will pay.

The present medicare program does not meet the health care needs of the elderly with prolonged or chronic illness, as it was designed and is regulated as an insurance program for the elderly who are acutely ill (Brickner et al., 1987). Medicare handles long term, chronic health care problems poorly. The recently passed legislation which provides for Catastrophic Health Insurance does not improve assistance for chronic health care, as it is designed "solely to insure against the catastrophic expenses of those under treatment in acute care hospital beds for prolonged periods" (Brickner et al., 1987).

Brickner and associates (1987:300) see catastrophic health insurance as a laudable first step, but point out that "The proposal [now law] fails to respond to the demographic imperative of the aging in this country and the need for additional amendment of the medicare law to insure against the much more common catastrophic costs of care for chronic disease." They point out that the current mind set in Washington tends to produce negative legislation. Attention is on the massive federal deficit which is seen as producing a cold climate to innovation and long term thinking. Since 1975 Congress has made unsuccessful attempts to pass home health care bills. The proponents of these bills were Representative Edward L. Koch (Dem-NY) in 1975, and more recently Senator Orrin G. Hatch (Rep-Utah). The importance of

proper timing is stressed by Brickner et al. (1987). They suggest that now may be the wrong time to propose significant Medicare entitlements because of the political cycle through which we are presently moving. During Reagan's administration there has been an increased shift in Congress away from enacting new health policy programs and toward legislative cutbacks. These researchers anticipate a period of thinking and planning extending into the mid-1990's before the political timing might be right for legislative reform. This time projected for political readiness can well be utilized by helping professionals and researchers to formulate clear goals and reach consensus on programs for the elderly; ones that legislators will feel are workable and fiscally sound.

Issue for future research

This study supports previous research which indicates high levels of involvement of family with their institutionalized elderly, but calls into question the idea that relief from direct care which comes with placement improves family relations. Caution is taken not to generalize the results of this study because of its small number of subjects and its exploratory and descriptive nature. Additional research is needed to extend and test concepts presented here and in other studies concerned with the family of the institutionalized elderly. The following related research issues for future consideration are suggested:

- research on the effects that type of ownership and organizational arrangements have on relationships of the

family and the elderly resident. Does it make a difference in how families relate if the nursing home is religious or secular; non-proprietary or proprietary? Are there other factors about the organization of the institution which tends to positively or negatively affect family relations?

- research on the three levels of family involvement culled from this study. Can these levels of involvement be identified in other settings? If so, how can they be specified more clearly? Does the level of involvement differ by, for example, kin (spouse, sibling, offspring)? Sex? Previous relationships?
- research on communication styles between the resident and family member. Details are needed on the circumstances surrounding elderly who acquiesce. What are the survival outcomes of the elderly who acquiesce as compared to those who do not? Do family members consistently feel less internal conflict when their elderly family members acquiesce?
- research designed to more specifically document exchange relationships between the family and resident, looking particularly at the resident and what she provides, if anything, to balance the exchange relationship.

Whether the frail elderly is in the community or in an institution, family members tend to stay involved, providing both affective and instrumental needs. If the family is provided with support to deal with the economic, social and emotional problems surrounding the long term

care of their frail elderly, everyone will benefit. The elderly cannot be viewed in isolation from her family. The "optimum care policy for enhancing family integration is one that actively recruits the family and services the family as a client . . . " (Montgomery 1982:58).

APPENDIX A
INTERVIEW PROTOCOL FOR RESIDENT AND FAMILY MEMBER(S) SURVEY

CASE # _____ NURSING HOME CODE # _____
RESPONDENT: _____ RESIDENT _____ FAMILY MEMBER (WHO) _____

NOTE: This protocol serves as a general interview guide and is organized so that the major areas of inquiry are indicated followed by questions which will be introduced. Words and phrases under questions are intended as prompts for the investigator in the event that the points are not spontaneously addressed by the respondents. Except in the few instances of forced choice questions, the researcher will exercise the freedom to vary the wording and sequencing of questions to specific respondents in the context of the actual interview.

I. The Nursing Home

These questions concern the decision about the nursing home and your feelings about things then, and now that you (your relative) are here (is there).

1. Let me ask you some of your thoughts about the nursing home. What are some of the things you really have liked?
physical care
food
social programs
facilities
accommodations
privacy
2. What about dislikes?
3. What about the staff? What have you really liked about the staff?
4. What have you really disliked about the staff?
5. What do you think about the way the administrator runs this home?
6. What is your opinion about how what he thinks and does affects what happens here? Examples?
7. What about the nursing director? What do you think about how she/he handles nursing issues? Examples?
8. How does she/he affect what happens to you here? Examples?
9. I am wondering what kinds of things you would like to do with or for your family which are prevented by the rules of the home.

10. Please tell me how the idea of the nursing home came about.
- when
 - persons involved
 - level of agreement
 - events
 - conditions
 - feelings
 - adverse changes
 - health (ADL)
 - economic
 - social (death, relationship change)
 - living arrangement
 - possible alternatives
11. Thinking about you and the family, if I'd been there, what kinds of problems would I have seen you having?
12. At that time, what was the most difficult thing about your care for you and your family? (Caring for your elderly family member?)
13. Try to recall for me what kinds of thoughts and feelings you were having at the time the decisions were being made to enter the nursing home.
- *fear **regret
 - *depressed **relief
 - *abandoned **guilt
 - anger **failure
 - helpless
 - hopeless
 - (*always asked of resident,
 - **always asked of relative).
14. Who or what was most helpful during this time when changes in living arrangements were being considered?
15. What are your feelings about the placement now that you (your relative) are here (is there)? (cues as in #13).
16. What do you know now that you wish you had known at the time you were making decisions about the nursing home?
17. If you had the power to change things at the nursing home, what would you make different?

Questions 18-20, for family only.

18. What was the primary reason for this placement?
- 1=medical or psych. 6=P.C.G.'s work duties
 - 2=economic (no funds for 7=P.C.G.'s family duties changed
 - alternatives to N.H.) (birth, move, etc.)
 - 3=legal (committed) 8=family tensions too high
 - 4=P.C.G.'s health changed 9=other, specify _____
 - 5=companionship was needed 0=unable to say, don't know
 - (P.C.G.=primary care giver, e.g., spouse, child)

19. From your knowledge, when nursing homes were first discussed by the family or ...(the resident)... what was ...(the resident's)... attitude toward the nursing home in general?
- | | |
|-----------------------------------|-------------------------|
| 1=definitely negative | 4=probably positive |
| 2=probably negative | 5=definitely positive |
| 3=no attitude was evident | 6=resident did not know |
| 0=unable to say, don't know, etc. | |
20. Who do you think had the most influence in the decision to place ...(the resident)... in a nursing home?
- | |
|--|
| 1=resident |
| 2=guarantor or family member to be interviewed |
| 3=another family member |
| 4=neighbor or friend |
| 5=physician |
| 6=pastor |
| 7=social worker |
| 8=other, specify _____ |
| 9=no single individual can be selected |
| 0=unable to say, don't know, etc. |

Questions 21-23, for resident only

21. What was the main reason you came to a nursing home?
- | | |
|----------------------------------|----------------------|
| 1=medical treatment | 5=family/P.C.G works |
| 2=Medicare didn't cover services | 6=family tensions |
| 3=P.C.G. died | 7=other _____ |
| 4=was living alone | 0=unsure, don't know |
22. When you first thought about going to a nursing home, how did you feel toward nursing homes in general?
- | | |
|-----------------------|-----------------------------|
| 1=definitely negative | 4=probably positive |
| 2=probably negative | 5=definitely positive |
| 3=I didn't care | 0=unable to say, don't know |
23. Who do you think had the most influence in the decision for you to enter into a nursing home?
- | |
|--|
| 1="I did" (respondent/resident) |
| 2=person cited as nearest relative |
| 3=another family member |
| 4=neighbor or friend |
| 5=physician |
| 6=pastor |
| 7=social worker |
| 8=other, specify _____ |
| 9=no single individual can be selected, etc. |
| 0=unable to say, don't know, etc. |

Other comments.

Questions 18-23 are taken from the 1984 Florida NURSING HOME PLACEMENT STUDY by Bradham, D. and Pendergast, J.

II. Family association.

We are interested in finding out what kinds of things people do with their family members who are in nursing homes, and how that is different or the same as before entering the nursing home.

1. Living family members and their locations:

☐ Spouse	☐ Gainesville	☐ Florida	☐ other _____
☐ Sons	☐ Gainesville	☐ Florida	☐ other _____
☐ Daughters	☐ Gainesville	☐ Florida	☐ other _____
☐ Brothers	☐ Gainesville	☐ Florida	☐ other _____
☐ Sisters	☐ Gainesville	☐ Florida	☐ other _____
☐ other sign.	☐ Gainesville	☐ Florida	☐ other _____
2. Community living arrangement of resident prior to entering nursing home (or other institution).
3. What kind of contact did you have with your relative before the nursing home? Frequency?
 - visit
 - telephone
 - letter
 - messages
 - other (specify)
4. If you lived apart, what occasions brought you and the family together?
 - special occasions
 - family reunions
 - vacation visits
 - emergencies
 - others
5. What kinds of activities did you and the family engage in before the nursing home?
 - outings
 - games
 - commercial recreation
 - home recreation
 - outdoor recreation
 - visiting for conversation
 - shopping
 - church
 - eating out
 - helping
6. What kind of contact do you have with your relative now? (cues as in #3)
7. What kinds of things do you do together now? (cues as in #5)
8. Tell me about the last time you had contact with your relative. When was that, and what did you do?

III. Family exchanges

Family members help each other in many different ways. It could be little things you do for them, it could be money, giving things, lending a hand by helping out with something, or sharing knowledge, advice or comfort when there are problems. We would like to know how you and your family help each other.

1. What kinds of help did you provide (relative/resident) before the nursing home admission?
2. What kind of help did you receive from (relative/resident) before the nursing home admission?
3. What kinds of things have you been able to do for (relative/resident) since the admission to the nursing home?
4. What kind of help have you received from (relative/resident) since the admission to the nursing home?
5. What kinds of things would you like to do for (relative/resident) if it were in your power?
6. At what point in your life was (relative/resident) most helpful to you? Explain.
7. What sacrifices would you say you have made for (relative/resident) in the past?
8. What sacrifices would you say you are making now?
9. What sacrifices would you say (relative/resident) has made for you in the past?
10. What sacrifices would you say (relative/resident) is making for you now?

IV. Family sense of duty

Let's discuss what it is that keeps you more or less involved with your family.

1. What are some of the reasons you can think of which makes you want to stay in touch with (relative/resident)?
2. What is your opinion about whether relatives should be concerned about each other's affairs?
3. What kinds of responsibility do you think family members should take for each other?

V. Family affectional feelings

With these questions we want to look at how family members relate to each other.

1. How well can you exchange ideas or talk about things that really concern you?
2. What kinds of important ideas and opinions do you agree about?
3. What kinds of important ideas and opinions do you disagree about?
4. What kinds of concerns do you have about (relative/resident)?

5. Do you see/hear from (relative/resident) as often as you would like?
6. What are the things that affect how often you have contact?
7. Tell me about the time in your lives when you were most close.
8. Have there been changes in your feelings of closeness lately?
Explain?
+/-
before, with, after placement
source
9. How would you describe your present relationship?
10. What kinds of things have seems to affect your present feelings of closeness?
past behavior +/-
physical condition
mental condition
attitude
11. I am going to name some feelings people often have about each other. Tell me what they mean in your relationship.
affection trust
fairness respect
understanding
12. Taking everything into consideration, how close would you say you are in your feelings toward (relative/resident)?
13. Given the matter we have been discussing, is there anything you think I should have asked, or I have neglected?

Respondents:

Age: below 44 45-54 55-64 65-74 75-84 above 85
 Race: White Black Hispanic Other (specify)
 Education completed: grade school high school college
 advanced degree

Last job: _____

This ends the interview. Thank you for your participation. May I contact you again should I need more information?

APPENDIX B
NURSING HOME RESPONDENT SURVEY

Case ID Number: _____
Home ID Number: _____
Date Completed: _____

I ask your assistance in completing this questionnaire. Please give the response to the following questions which you feel to be most accurate based on your knowledge and observations of this resident and her family.

1. This resident sees a family member:

☐ Every day	☐ Every three months or less
☐ Every week	☐ Never
☐ Every month	☐ Other (specify) _____
2. This resident talks to family by phone:

☐ Every day	☐ Every three months or less
☐ Every week	☐ Never
☐ Every month	☐ Other (specify) _____
3. This resident and family engage in these activities together (check all items that apply):

☐ Hold conversations	☐ Go shopping
☐ Go to church	☐ Go to lunch/dinner
☐ Go on outings/trips	☐ Read
☐ Play games	☐ None of the above
☐ Other (specify) _____	
4. This resident helps her family in the following ways (check all items that apply):

☐ Gives gifts	☐ Gives money
☐ Gives advice	☐ None of the above
☐ Comforts	☐ Other (specify) _____
5. This resident's family helps her in the following ways (check all items that apply):

☐ Gives allowance (money)	☐ Gives gifts
☐ Provides personal items	☐ Pays for care at nursing home
☐ Pays medical bills	☐ Helps with personal care
☐ Gives advice	☐ Takes care of business affairs
☐ Comforts	☐ Brings food
☐ Decorates room	☐ Does shopping
☐ None of the above	☐ Other (specify) _____

6. This resident gets along well with the nursing home staff:
☐ Strongly agree ☐ Agree
☐ Cannot say ☐ Disagree
☐ Strongly disagree
7. This resident gets along well with other residents:
☐ Strongly agree ☐ Agree
☐ Cannot say ☐ Disagree
☐ Strongly disagree
8. This resident is satisfied with her care at this home:
☐ Strongly agree ☐ Agree
☐ Cannot say ☐ Disagree
☐ Strongly disagree
9. This resident's family is satisfied with her care at this home:
☐ Strongly agree ☐ Agree
☐ Cannot say ☐ Disagree
☐ Strongly disagree
10. This resident has adjusted well to being in this home:
☐ Strongly agree ☐ Agree
☐ Cannot say ☐ Disagree
☐ Strongly disagree
11. This nursing home policies make it easy for the resident's family to stay involved with her:
☐ Strongly agree ☐ Agree
☐ Cannot say ☐ Disagree
☐ Strongly disagree

The following questions refer to the residents' activities of daily living, now and at the time of admission. Please check the appropriate answer.

This resident:

1. Require(d) assistance with bathing:
 Now ☐ yes ☐ no ☐ don't know
 On admission ☐ yes ☐ no ☐ don't know
2. Require(d) assistance in dressing:
 Now ☐ yes ☐ no ☐ don't know
 On admission ☐ yes ☐ no ☐ don't know
3. Require(d) assistance in eating:
 Now ☐ yes ☐ no ☐ don't know
 On admission ☐ yes ☐ no ☐ don't know
4. Is (was) bedridden:
 Now ☐ yes ☐ no ☐ don't know
 On admission ☐ yes ☐ no ☐ don't know
5. Require(d) assistance in walking:
 Now ☐ yes ☐ no ☐ don't know
 On admission ☐ yes ☐ no ☐ don't know
6. Require(d) assistance in toileting:
 Now ☐ yes ☐ no ☐ don't know
 On admission ☐ yes ☐ no ☐ don't know

7. Has (had) difficulty controlling bowels:
Now ☐yes ☐no ☐don't know
On admission ☐yes ☐no ☐don't know
8. Has (had) difficulty controlling bladder:
Now ☐yes ☐no ☐don't know
On admission ☐yes ☐no ☐don't know

Thank you for your cooperation. Please add any comments which you feel will be helpful.

APPENDIX C
INFORMED CONSENT FORM

I UNDERSTAND THAT THE PURPOSE OF THIS STUDY IS TO INVESTIGATE THE IMPORTANCE OF THE FAMILY FOR PERSONS IN NURSING HOMES. I HAVE BEEN INFORMED THAT ALL RESPONSES ARE VOLUNTARY AND UNDERSTAND WHAT WILL BE REQUIRED OF ME AS A SUBJECT.

I CONFIRM THAT MY PARTICIPATION AS A SUBJECT IS ENTIRELY VOLUNTARY. NO COERCION OF ANY KIND HAS BEEN USED TO OBTAIN MY COOPERATION. I MAY WITHDRAW MY CONSENT AT ANY TIME WITHOUT PREJUDICE.

I UNDERSTAND THAT MY RESPONSES, WRITTEN OR RECORDED, WILL REMAIN COMPLETELY ANONYMOUS AND CONFIDENTIAL.

I HAVE READ AND UNDERSTAND THE PROCEDURES DESCRIBED ABOVE. I AGREE TO PARTICIPATE IN THE PROCEDURE.

SIGNATURE:

(SUBJECT)

(DATE)

(WITNESS)

(DATE)

PRINCIPAL INVESTIGATOR:

GLORIA B. CALLWOOD

UNIVERSITY OF FLORIDA

GAINESVILLE, FLORIDA 32611

PHONE: (904) 392-3531 (904) 376-0072

APPENDIX D
RESPONDENT'S RELEASE OF INFORMATION FORM
(FOR USE IN TELEPHONE INTERVIEWS)

"I AM GLORIA CALLWOOD. TODAY IS _____, I HAVE EXPLAINED THE
PURPOSE OF THE NURSING HOME STUDY TO MR(S) (RESPONDENT'S NAME).
MR(S) (RESPONDENT'S NAME) HAS AGREED TO PARTICIPATE IN THE STUDY
WITH THE UNDERSTANDING THAT INFORMATION GAINED IS CONFIDENTIAL AND WILL
BE USED FOR RESEARCH ONLY. FURTHER, (S)HE UNDERSTANDS THAT ANY QUESTION
MAY BE REFUSED SHOULD (S)HE CHOOSE TO DO SO. MR(S) (RESPONDENT'S
NAME), WOULD YOU PLEASE STATE YOUR NAME AND THAT YOU AGREE TO
PARTICIPATE AND TO BE RECORDED? (RESPONDENT'S RESPONSE)."

APPENDIX E
LETTER OF INTRODUCTION

Summer, 1984

To Whom It May Concern:

Many questions have been asked recently concerning the family relationship of people in nursing homes, and a group of researchers at the University of Florida is now undertaking a major research project on these issues.

This letter will introduce Gloria B. Callwood, my research associate. Ms. Callwood will be interviewing selected residents of Florida nursing homes, their closest relative(s), and a professional at the nursing home who has been closely involved with the resident. I am writing today to ask if you would be able to participate in our study.

Participation of the resident and her family is entirely voluntary, and consent may be withdrawn at any time. The interview will take about an hour, and will be tape recorded to assure accuracy. All information received, whether written or recorded, will be kept anonymous and confidential. No identifying data will be included in any report of this research.

I assure you that Ms. Callwood's background as a professional nurse with over twenty years experience in the health field has prepared her to relate to the respondents with consideration and sensitivity. I anticipate no adverse effects and feel confident that this research project will be able to shed light on a number of issues that are important for nursing home residents and their families.

Thank you in advance for your assistance in helping us improve the quality of nursing home care.

Sincerely,

Gordon F. Streib, Ph.D.
Graduate Research Professor

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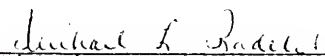
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BIOGRAPHICAL SKETCH

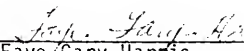
Gloria Brooks Callwood was born July 16, 1939 in Arredonda, Florida, of Karlene and Haynes Brooks. The product of a segregated school system, she received her elementary and secondary education in Gainesville, Florida, graduating salutatorian from Lincoln High School in 1957. In 1962 Gloria received a B.S. degree in nursing from Hampton Institute, magna cum laude. She earned a master's degree in nursing at the University of Florida in 1977.

Gloria is employed by the Virgin Islands Department of Health as a psychiatric nurse consultant. She is married to Richard Callwood, Jr. They have eight children and reside in St. Thomas, U. S. Virgin Islands.

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.


Michael L. Radelet, Chairman
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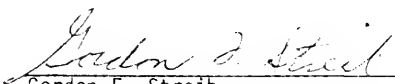
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Professor of Nursing

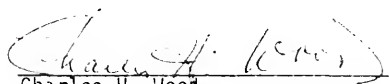
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This dissertation was submitted to the Graduate Faculty of the Department of Sociology in the College of Liberal Arts and Sciences and to the Graduate School and was accepted as partial fulfillment of the requirements for the degree of Doctor of Philosophy.

December 1988

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